CORRECTED TRANSCRIPT

REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON SOCIAL ISSUES

INQUIRY INTO SERVICES PROVIDED OR FUNDED BY AGEING, DISABILITY AND HOME CARE

At Sydney on Monday 9 August 2010

The Committee met at 9.30 a.m.

PRESENT

The Hon. I. W. West (Chair)

The Hon. G. J. Donnelly
The Hon. M. A. Ficarra
Dr J. Kaye
The Hon. T. J. Khan
The Hon. Helen Westwood

CHAIR: I declare the hearing open. I welcome you to the first public hearing of the Standing Committee on Social Issues inquiry into services provided or funded by Ageing, Disability and Home Care. Today we will be hearing from Ageing, Disability and Home Care, the Disability Council of New South Wales, National Disability Services, New South Wales Carers, and the Council of Social Services of New South Wales.

I advise that the Committee has previously resolved to authorise the media to broadcast sound and video excerpts of its public proceedings. Copies of guidelines governing broadcast of the proceedings are available from the table by the door. In accordance with Legislative Council guidelines for the broadcast of proceedings, a member of the Committee and witnesses may be filmed or recorded. People in the public gallery should not be the primary focus of any filming or photographs. In reporting the proceedings of this Committee the media must take responsibility for what they publish or what interpretation is placed on anything that is said before the Committee.

Delivering of messages and documents tendered to the Committee should be done by way of the staff. I advise that under the standing orders of the Legislative Council any documents presented to the Committee that have not yet been tabled in Parliament may not, except with the permission of the Committee, be disclosed or published by any member of such Committee or by any other person. If you should consider at any stage during your evidence that certain evidence or documents you may wish to present should be heard or seen in private by the Committee, the Committee will consider your request. However, the Committee or the Legislative Council itself may subsequently publish evidence if it decides it is in the public interest to do so. Please turn off any mobile phones. I welcome our first witnesses.

MARIE NEW, Regional Director, Hunter Region, Ageing, Disability and Home Care, and

LAUREN MURRAY, Deputy Director General, Ageing, Disability and Home Care, and

JAMES CAMERON MOORE, Chief Executive, Ageing, Disability and Home Care, and

ETHEL McALPINE, Deputy Director General, Ageing, Disability and Home Care, sworn and affirmed:

CHAIR: Do you want to make some opening comments?

Mr MOORE: Briefly, I put on the record that we welcome the chance to talk to the Committee about the matters identified in relation our department. Ageing, Disability and Home Care is a very large part of the Human Services department of New South Wales and is about the fourth largest agency in New South Wales. We have gone through a very substantial growth and reform period over the past four or so years. In our submission, you will see that as an agency since 1998 we are now 120 per cent bigger. We have more than doubled in size. Over the past five years what has been driving our growth is much less cost of service delivery as opposed to expansion of service delivery. We know we have made a very substantial difference to the lives of a larger number of people with disability and their families. We are also well aware of the need to do a lot more both in terms of our own performance and in terms of being able to do additional services.

We as an agency are predominantly, in terms of size, overseeing dollar size, about $1.9 billion that we spend on specialist disability services, about $550 million that we spend on home community care services and a small number of millions of dollars—to the tune of $10 million to $15 million—we spend on various services for what we would refer to the well-aged things ranging from Senior's Week events and seniors concerts, Seniors Card and those sorts of things and a small amount of ageing grants. But our business is predominantly about assisting about 50,000 families and people with a disability with specialist disability services, and about 250,000 generally frail older people but there are some people with a disability who get home and community care services.

As we will talk about later and I am sure in response to questions, we have in the disability space been making significant improvements in terms of our understanding of population but we do suffer from a paucity of data in this area. We only have a once-in-six-year chance to see the totality of the population of people with a disability in New South Wales, through an ABS survey, and that we do our best to try to model out an understanding of just what is the level of need and what is the right way to respond to that need in that context, but our position is somewhat limited. I put that up front because I fear that there is enormous frustration about the ability of the agency to be able to point to just how well we are doing against population data, but it is a very difficult issue which has been recognised nationally. There is underway national-level work through the Council of Disability Ministers and other work is underway in the Productivity Commission through referral to them. I will endeavour to do my best to address the terms of reference for you.

My submission has tried to give you as clear a summary as we can of the situation. But I do want to acknowledge that we have experienced in terms of discussions with members of the public, families and others that there is a fairly significant level of frustration about our ability to quantify just what is the level of unmet need that should be met by government.

The Hon. MARIE FICARRA: Mr Moore, you said that you realise there is a lot more that needs to be done by the department. Will you advise the priority areas where you believe that more services need to be provided?

Mr MOORE: There is clearly a need for additional services across a range of supports that we provide. That is acknowledged in the Government's 10-year reform program called Stronger Together. It is also evident in terms of requests to us from people. There is a very significant level of expressed need for what we would refer to as supported accommodation which is generally a reference to supporting people with a disability in an arrangement where paid workers provide most of the care. I think that we also need that when you look at respite, therapy, day programs, services that are critical to people with disability and their families continueing to remain close together that again there are more requests for services than we are able to meet. I also think in terms of what more needs to be done that it is not just a matter of what we can do as a specialist disability provider to provide services but there is clearly a need to change how the services are delivered. There is a growing expressed desire for people with a disability and their families to have much greater control of how resources available to them are applied. That is an area where, when you look at it both from a program administration perspective and also from areas like looking at it from the human rights United Nations convention which talks about enabling people with a disability to be in control of their lives, we need to change our administration quite substantially.

There is a range of things that we are doing to work our way towards that. In addition to being able to administer our arrangements much better we also need to work with other parts of the broader community and social environment. We have got to make sure that we do not have people with a disability and their families looking solely to a specialist disability service provider for help to get a life, to get a better life, and to be involved in the community. We need to look to the community, we need to look to other parts of the government service system, and that is a substantial and ongoing piece of work that I would say we have not been able to do enough on, that as an agency we have been heavily focused on the issues to do with rolling out more services and making those services work better.

I think that in order to get better outcomes we need to also be working on how we can make the community generally more able to support people with a disability. Just to give you one simple example, I would much rather see a person being able to get engagement with the community by being able to participate in a club rather than having a paid worker take them. Like fishing, I would much rather the community respond to that than for us to have a paid worker doing it. Those are challenges that I am sure you would all be familiar with.

The Hon. MARIE FICARRA: Just following on from how services are delivered and finding better models for that and also when you touched on supported accommodation, are there overseas models where this is being done? The only overseas model I have got experience with is in the province of Alberta in Canada, which I found did a particularly good job with supported accommodation. But are there models that the department is looking at and perhaps in the future direction?

Mr MOORE: Yes, we are looking everywhere and endeavouring to mine the international and national pictures of what are appropriate ways to provide supported accommodation. There are two particular areas which are for us priorities and one of those is in the space of being able to provide accommodation with much less intensive models. The history of specialist disability services in New South Wales has seen a very strong preference over the last dozen years or so with group-home style accommodation and being able to make that work well. That is an important model but it is not the only one and it involves generally quite intensive levels of support that not everybody who needs accommodation and life supervision outside of the family home needs the level of intensity that a group home applies. So we have been trying to build our repertoire particularly of what we might call drop-in accommodation where you do not have 24/7 arrangements.

We also are looking at a variety of support models which address very specific sorts of needs of people that a very broad-based general system cannot, and they fit into a couple of examples. One would be where we work with a smallish number, a couple of hundred people who have exited the criminal justice system and have got significant disabilities and we have been building models that provide them with a framework that has successfully reduced recidivism. I think we have gone from an average of seven to two with them. That is a very specialist and targeted group. We also have to deal with the fact that there are a small number of people with a disability who need incredibly high levels of medical and allied health support and we have got to be able to find the right way in which they can be delivered. Key to that is being able to access quality nursing, and that is not possible within the current employment arrangements and the way in which nurses work in highly devolved small-scale facilities. We are looking at different models around how to do that as well.

More broadly, a model that we are very keen to be able to roll out when we have got a very clear methodology of doing so is one which I suspect you may have seen in the Alberta context and it is one that is important, which is often called the flexible accommodation model where there is an individual funding package for accommodation which enables a person with a disability and their family to work out, within a fixed envelope of resources, what to do. We have done a couple of very special examples in really specialised circumstances around that. We would like to be able to do a lot more. At the moment we have been focusing, however, on the rollout of accommodation, on getting the built-up level of demand that was apparent before the reforms that came through in 2006, being able to get those models out. The response to those was predominantly in the group home case as we are moving towards the last year of the current five-year phase of growth funding. We are now moving to introduce a lot of those that involve the drop-in support models and now we have got a clear sense of the policy settings that we would like to adopt, we would like to see going into the future the introduction of more flexible models, including individual funding arrangements.

But for me one important point of this space is that with individual funding models, even where there has been a lot of flexibility made available in the English circumstance, you see a relatively small proportion of people take it up. We have one experience where in recent years our attendant care program, which provides fairly intensive generally in-home support for a person, we now say if you want it you can have the money direct into your bank account—the ultimate flexibility in a way. Of the just over 700 people that we have, 18 have elected to take up the arrangement, and that is a reflection that people need a lot of help and support, not necessarily from the government; they need a lot of help and support to manage a package and we also need to make sure that where people are managing those packages they get what they want, otherwise you give them flexibility but if there is no choice then in actual fact it is a false sort of offering.

While a very small number of people take it that is not an issue, but for us—and I go back to my opening remarks about trying to put into effect the United Nations Convention—if you want choice, no matter how people are being funded, you want people to be able to have the control over what happens with the resources to be in control of their lives even if we are not providing the individual funding arrangement. So for us we need to make sure that across the board we can manage a supply system of services that meet people's needs. In very recent times, in June of this year, after some very extensive work with the disability sector we have released an industry development plan and that plan puts a lot of emphasis on being able to put the person with a disability at the centre of the system rather than the services and it provides us with a framework for being able to manage the development of the supply of services in the context where there is much more choice about what people want.

At the moment the service system operates very efficiently because what you have is provided with guaranteed streams of funding and that makes it very easy for them to take on the risk of employing staff and investing and so on. The more you introduce choice then the more difficult it is for them to take on those risks, which are very substantial for them, and we have to find another way of operating. What I am pleased about in the New South Wales context is that over the last few months in a constructive, collaborative way with the sector we have been able to come to an industry development setting that I think will be a key plank in being able to move the service system to be more driven by what people want rather than what services can be supplied.

CHAIR: Could you elucidate on that a bit? When you put the person in the centre, which I do not think anyone would disagree with, the issue then is how you determine and ensure things like quality of service, amount of service, the actual training of those particular services that have been provided, the actual issue of free choice versus freedom to choose—which are two fundamentally different things. You can have the freedom to choose but if you have not got anything to choose there is not much point having the freedom. There does not appear to be a lot of work getting to the bottom of how you ensure not only the quality of service that is being provided in terms of some monitoring and grievance procedures over how you determine the skill of the service being provided, how the skills are being obtained, who does the skilling, who does the training, are the people just people with good intent that come to give the aged person their intensive personal care, and who is accounting for the amount of funding that is needed for skilling, because all the documents appear to be talking about all these very skilled employees and I am having difficulty seeing where they are being skilled?

Mr MOORE: I think they are some of the most significant issues that we have to deal with in terms of the theory of what we are talking about. That is why in the New South Wales context we have chosen not to move rapidly down the path of individualised funding. We have done quite a bit in little places but it has not become a whole scale system setting because we need to solve the issue of where the workforce is going to come from and how we are going to get the right skill and quality of workers. In 2007 we were witnessing a significant labour shortage within the specialist disability system. We know that specialist disability services are not generally the sector of choice for employees and that there are a lot of employees, prospective employees, who choose care work but they tend to choose care work in the aged care sector rather than in the specialist disability service sector. That led us to make an investment through the National Disability Services organisation on a campaign that became the carecareers campaign, which was trying to underpin how we develop our workforce, how we attract our workforce, how we retain it, not just as an agency but across the whole of the sector.

CHAIR: When you say "we", what do you mean?

Mr MOORE: I would use "we" as any employer in the disability sector.

CHAIR: I understand that you are trying to divest your employer status to NGOs and other organisations. Therefore, you are becoming less and less of an employer.

Mr MOORE: ADHC has a workforce of around 14,000 people. The vast majority of those work as care workers in a group home network we run where we have over 2,500 clients being helped by about 3,500 staff. We have a Home Care Service of New South Wales that employs 4,500 staff.

CHAIR: I am sorry, you have?

Mr MOORE: Yes. The Home Care Service of New South Wales is part of my empire.

CHAIR: I thought that was a statutory authority and that you were divesting yourself of those responsibilities?

Mr MOORE: No, no. If I could just finish the description of our labour force, I will come back to that. We have a Home Care Service of New South Wales, which is a statutory authority that effectively is integrated into the agency. It has 4,500 staff. We have a set of large residential services. We have got about another 2,500 nurses in it. We also have a therapy case management workforce of around 8,000. We have divested ourselves in recent times only of a day program service. We are running about 30 day programs. We have transferred those to the non-government sector. But we do not have a whole scale divestment program. What we do have, which I think is what you are referring to, is a decision that was taken by the Council of Australian Governments earlier this year as part of the hospital and health reform arrangements to change how the home and community care program in particular is funded. Instead of us being jointly Commonwealth-State, that money is being placed into the hands of the States, where basically 70 per cent of that funding goes to people who are over 65 and 30 per cent goes to people under 65. The Commonwealth is now going to retain that funding for itself rather than passing it through us.

That has led to speculation as to what would happen to the Home Care Service of New South Wales, which is fully funded out of Home and Community Care funds. The Commonwealth has committed as part of the COAG arrangement to no substantive change in service delivery arrangements for at least five years. That would give us time to talk about just what that would mean for the Home Care Service of New South Wales and also for all the rest of the home and community care sector. There are about 600 organisations that get those sorts of funds and the Home Care Service of New South Wales is around 30 per cent of the totality of the HACC sector in New South Wales. It is the single biggest provider in New South Wales and Australia. But it is acknowledged also, I would have to say, informally by senior Commonwealth officials, as being efficient. Were anyone to think about choosing to deliver home and community care services other than by relying on the Home Care Service of New South Wales, effectively by definition they would be looking to spend more money for less services or the same amount of money for less services because the Home Care Service has managed to evolve into a very efficient operation that has significant economies of scale built into the way it operates. It has the capability of going anywhere in New South Wales. It delivers services to people in very short time blocks, if that is what is required. It will take on clients that nobody else will take on. It will take on clients who need to go to bed at 11 o'clock at night, if that is what is required. Its strength in the overall operation cannot be underestimated.

CHAIR: Does the definition of "efficiency" include the question of flexibility and the ability to actually train their staff?

Mr MOORE: The Home Care Service of New South Wales has some ability to train staff and better within its funding.

CHAIR: Some ability?

Mr MOORE: Yes, some ability. I think that across the board within the HACC system and the specialist disability system, and beyond, but across those two, the need to invest more in staff skills is very evident.

CHAIR: Is that less so with Home Care Service of New South Wales than the 600-odd NGOs?

Mr MOORE: I would expect that on average because the Home Care Service is big, because of the natural way in which big organisations operate compared with a lot of smaller ones, we would probably do a bit more than the non-government sector. We certainly know in the disability side of our business that the conversation with the NGO representatives is how we will be able to better share resources on skill development so that we can pull ourselves all up together, so to speak.

The Hon. HELEN WESTWOOD: Earlier you talked about the paucity of data and how difficult that makes the department's job in planning the level and type of services that people with disabilities are going to need. Is there any overseas evidence or experience that is more reliable than the data sources we have in Australia or New South Wales? Are we seeing different patterns of the incidence of disability in democracies similar to ours?

Mr MOORE: From the advice that has come to me, I would not say there is anything good or bad about other countries in terms of data. My point earlier was that in order to do the sort of business that we are doing from time to time you need to be able to see your performance against the totality of the population. We only get a once-in-every-six-year window to look at that data. There are discussions underway, which may enable us to change that. In 2008 the National Disability Agreement came into place. That is leading to a sharper level of discussion at the Commonwealth, States and Territories level as to how important acquiring more data is. There are a number of projects, several of which New South Wales is leading, in trying to develop a better understanding of the level of unmet need. We have done a lot of modelling work within New South Wales, which is now being extrapolated nationally. But all of those models run into a difficulty that if you can only ever see once every six years how you perform against the totality of the population you really cannot manage to finetune your judgements about whether you are improving in the level of service, reducing the level of unmet need, whether carers' needs or people with disabilities needs are changing such that you need, despite writing a program in that direction, to start recalibrating to a different direction. The discussion underway at the moment is about how we will be dealing with the second five years of the 10-year plan of Stronger Together.

We built our modelling on the 2003 ABS data collection to do the initial five years of funding. We are having to build plans around the second five years on exactly the same 2003 data. The data the ABS has just collected for the replacement 2003 survey will not be available until early next year. It is not that the ABS is not trying hard; it is the circumstances, difficulty and complexity of the collection. We paid—collectively in this case "we" being State, Territory or Commonwealth governments—the ABS to double the sample size and expand the questions in order to get a better survey, but it just takes time to get that data. If I had my preference I would love to see once every two or three years such a survey enabling us to then get a good sense of the population and then ask some questions about whether our programs have performed well by seeing whether there are changes in population, expressed levels of need and other issues that people are showing up.

In the absence of that, we can try to extrapolate all we can from pieces of evidence about what it looks like in the United States or what is going on in the United Kingdom, but you cannot come back and ask, "What does that mean?" In New South Wales the single biggest question that people keep throwing at us is, "But have you met enough of the need? There is more need. You're not meeting enough." That one cannot be answered in an objective way by looking at the population data and service delivery data against that. You can look at it in other ways. You can try to model it out but, as you will see in our submission, the Australian Institute of Health and Welfare has done its best to extrapolate from ABS data what will be the level of unmet need. They tell us that nationally it is about 30,000 supported accommodation places that they believe the data says need to be met but are not being met.

That would mean, on just general population dynamics, 10,000 in New South Wales. I do not deny there is not a lot of unmet need, and I did not see 10,000 worth of unmet need. The AIHW finds it very difficult to be able to say, "We know that people say they want supported accommodation, but what of that do they imagine will be met by informal care arrangements rather than funded arrangements?" It is a very difficult thing to calibrate. If we look at our registers of requests for supported accommodation where people can ask, we will list them and that is the list we draw on to fill vacancies. We have about 750 people at the moment who are saying, were they to be asked, they could accept a place immediately. We have another thousand who would say they would like a place sometime in the future. It is still a long way to go from there to get to 10,000.

For my mind, getting to the technical side of data, that is telling us that we do not have enough data to be able to go from the population level down to say that is what we should be doing. We can model it out in all sorts of ways, but it really does not help us in a community sense. We are giving people confidence in what we are doing. Nor does it help us as program administrators in being able to do that. Nor does it help government in being able to make decisions about priorities.

CHAIR: Could you elaborate on the definition of "need"? Rightly or wrongly, I interpret you to be saying that "need" somehow is defined on the basis of supported accommodation. Are you not saying that?

Mr MOORE: No, not at all.

CHAIR: As professionals in the area and in making an educated guess, as opposed to some scientific analysis, have you attempted to define "need" and what you think the need is? Firstly, what is the definition of "need"?

Mr MOORE: The definition we work with is the level of need for support that needs to be met by government intervention but is not being met. A person with a disability may need assistance with getting out of bed. That does not require government intervention in all circumstances for that to happen. So you have this very difficult issue to determine, which is not just whether there is an objective need but how best for that need to be met, government intervention or not. To answer how we define unmet need, it has to come down to quite a technical one of need required to be met by government intervention and not being met by government intervention.

CHAIR: Does your definition of "need" include the rather anecdotal terminology, if that is the correct word, that is used in many submissions we have received to describe a good life?

Mr MOORE: Yes. The simplest way to describe what we are in the business of doing is helping people with a disability get a life, get a better life, get a good life, get their life back—somewhere in that space. There are all sorts of bureaucratic expressions of that. The one I found works best is something in that space. It is not about helping them get a service because you do not need a service necessarily in all circumstances to get a good life. Indeed, there is a challenge in this space, which I think is a growing challenge for us because we are always looking in need of reminding ourselves that people with a disability are now living as long as anybody else in the community, on average. They have gone from very short life spans to now beginning to experience the same life span as the rest of us.

As a community we have to come to terms with how we make that into a good news story rather than a bad news story. As a community we are going to have to make a choice as to whether or not the way we do that is by providing funded services or whether we try to do it by building community and building capability of carers. You ask: How do you have a good life? A good life is delivered solely through funded services. It may be good, but it is not the same sort of life that the rest of us would have hoped for. How do you make plans; how do you make connections with the community? Through funded services. If that is all you have got, that is what you should get. But if there are other strategies for achieving that life would be much more sustainable for somebody's life. So, for us, unmet need goes certainly beyond supported accommodation. It is the thing that is most fixated on and it is the thing where there has been most work done, but it does need to go way beyond simply a question of supported accommodation.

Can I give you one example of this? We recently concluded an evaluation of our transition to work program, which was brought into being in 2006 as restructuring of ATLAS. ATLAS was for anyone who left school and was assessed as being unable to work. Because of their disability they went into ATLAS. The idea was to, if you could, work with a bit of effort to try to make that happen; if you could not, you were effectively in a day program-type service. In 2006 we broke the program into two parts and said that for those on our assessment criteria who were likely, with two years of effort, to be able to enter the workforce or further education, that was the program they went into. We did not mix it up with broader day programs.

We estimate that now there are between 1,000 and 1,500 people who are now in the workforce rather than a day program. Their needs are less than they might otherwise have been, and that is a good thing in terms of financial management for the government, but it is also a good outcome for the community. So there is a need to look at the need question way beyond just supported accommodation.

The Hon. HELEN WESTWOOD: I return to the issue of data and the need for reliable data. This goes some way towards your comment about it being beyond supported accommodation. Do you have enough data to be able to assist you to look at the development of a workforce in the disability sector? I know the sector is well beyond the department, but in terms of understanding what skills you will need in the workforce in a decade or in two decades, do we have data that is assisting you in those sorts of plans?

Mr MOORE: We have an okay set of data about what the nature of the workforce is at the moment. We recently completed a pretty decent survey of the broader community sector to understand the workforce. In the non-government sector there is a pay equity case that is now in front of the Fair Pay Commission. That pay equity case is, on the way it has been put, likely to see a very substantial increase in wages. As part of the preparation for that there is a collaborative effort among the sector players—the employers, the unions and the funders like the Government—to try to understand the exact nature of the totality of the workforce so that we can then begin to understand what the financial and other consequences of that workforce would be and what the pay equity case would be. Also, we can begin to think about how we can respond to that rather than simply as an issue of an increase in wages.

It presents a very significant opportunity to think about how we might be able to adapt the workforce and workforce planning issues so that we are able to address some of the skill issues that the Chair was mentioning earlier. It presents a great opportunity. I think there is a reasonable degree of goodwill among all the players to try to not denigrate the pay equity side of things but to say nonetheless this is a chance to think about how we move forward in a way that gets a better workforce as well. While this has been driven through pay equity, what we do know is that the non-government sector does receive somewhere in the vicinity of 20 or 25 per cent, on average, less on a point-for-point pay scale rate. They get certain advantages in terms of fringe benefits rates and so on.

But the thing that I always thought was the most informative piece of advice in terms of judgements around this is that the Productivity Commission has only once in its lifespan, so I am advised, said that there should be an increase in workers' wages, and that was in the not-for-profit report that it brought down last year. It had a really simple argument, a pure economics argument. It is what leads you to say: There is something substantial in this, that the not-for-profit sector is the second largest contributor to the Australian economy. It must grow. Its wages will not allow it to grow; therefore its wages have to go up.

CHAIR: However, the weekly remuneration for work performed is one side of the equation. Everyone in the industry is trying to assess how you deal with the issue of training and skilling people. Historically, it has been done in the government sector. I am trying to understand how it is being done, what money is being allocated, through whatever source, for non-government organisations to allocate sufficient money for skilling and training. In any event, that is coming back—

Mr MOORE: I can come back to that at another point, if you like.

Dr JOHN KAYE: The six-year period you refer to is census to census, is that correct?

Mr MOORE: No. It is a special survey of ageing and disability carers.

Dr JOHN KAYE: It is a cost issue that that does not happen more frequently?

Mr MOORE: It is a cost and capability issue for the Australian Bureau of Statistics. It has a very large program of surveys that it needs to digest, and in programming terms that is the way they have settled on the timing sequence for that. So it is not just a matter of cost; they have to have this space in their survey calendar to be able to do this. There are limitations to their workforce, and that is also a constraint. I think they are looking at other ways to try to assist us in this space. There is a strong recognition of the importance of that data. But these things can only be done carefully; you cannot simply turn surveys on and off if you are trying to build a body of data over the long term.

Dr JOHN KAYE: You are saying that you need consistency from one survey to the next, so that you can track changes?

Mr MOORE: That is an important part of it. You are also then going into people's lives. You have to pay some due respect to your intervention in people's lives in terms of what you do with the data. So they are very careful about how they build and change their survey program.

Dr JOHN KAYE: In terms of assessing and understanding the unmet need, that is the raw data. Are there other barriers to understanding the unmet need, apart from the infrequency of data?

Mr MOORE: Sometimes I get uncomfortable talking about people with a disability in system modelling and data terms in that something might not come out the right way. If you are trying to think about what you have to do to copy and model out unmet need you need to know how many people there are. That is what the surveys give you. There are good models and good practices on how you project that forward. So now you know how many people with disabilities there are. But you also need to know what it is that they need in the light of how you can intervene to change what they may need. I go back to the story I was telling you earlier about the 1,000 to 1,500 people who, had we carried on the old way, would now be in need of a lot more intensive support than they require at the moment.

You have to be able to also assess what is the efficiency and effectiveness of your interventions to change somebody's needs, to build on their strengths and their capabilities. You also need to be able to model what it takes to help carers and family members keep on caring to a reasonable level. There are not many families whose views of the world are such that they would have nothing to do with a person with a disability. That is an incredibly important part of how they will get a life, keep a life, and get a good life. There is not good data on just what interventions are effective—not just in the short term, but since we are talking about long life spans, what is good over the long haul. Then you have another difficulty as well. You also have to make a series of judgements about what are the appropriate interventions to change the general community environment in which people operate.

Understanding the numbers of people, and understanding how many of those people are getting services, is the easy bit. Being able to then extrapolate from that as to what is the right level of intervention as required, how much need is not being met, how much need needs to be met by government intervention, and what sort of government intervention—in respect of those things there is a real paucity of data, beyond even the stuff that I was referring to earlier about the fact that there is a survey only once in six years.

What we would advise government in this sense is that you would not plunge into this area without considering carefully what are the appropriate strategies to not simply meet need as expressed but to influence the capability of the community, the carers and the person with a disability themselves. I go back to my transition to work example. I would much rather see 1,000 people not in supported accommodation but in employment, where that is possible. That is not just a personal view; that would be a broad-based reference.

CHAIR: What do you say to the person who asks: If the department, or whoever should be monitoring, is successfully monitoring the industry and dealing with grievances and issues in the industry, should you not have ongoing knowledge of the needs and requirements in the industry anyway?

Mr MOORE: A lot of people do not talk to us. There are about 400,000 people in New South Wales who have severe or profound disability. That means they need help all or a lot of the time to be able to do basic living skills such as communicating, mobility, self care and personal care. How many of those people are people who come to us? We think we probably see, in terms of people with a disability, 50,000 or 60,000, in rough terms. How many of the rest need our help? I do not know.

CHAIR: What actions could the department take to work with non-government providers in order to better monitor requests for assistance and establish a more conclusive understanding of unmet need?

Mr MOORE: There is a lot of action underway in that space. In the last six months to a year we have been working very tightly with the non-government sector regarding the management of requests for supported accommodation, at a very high, consistent level. In addition to that, we have begun work around respite and accessing respite and trying to build a quite collaborative working arrangement on a region-by-region level around how we access respite, who is accessing, what would be the right response, and what is the best provider for dealing with that. Recently we have been through a performance audit with the Auditor-General of New South Wales around our respite booking and management arrangements. Basically, he has asked us to speed up our work to build a total booking system for respite.

Notwithstanding that effort, the NGO sector in New South Wales would be incredibly cooperative and is cooperative in working with us. We have a service system that is funded not just by government; there are a number of service providers that supply services through their own means, and these are sometimes non-trivial. The Spastic Centre of New South Wales would see itself as being, I suspect, substantially not funded by us. We have to deal with how you work with people. This is the part that is done by government funding. We are talking about vacancies and unmet need in that space and we also have other stuff over here that we are doing our way, and trying to build collaborative arrangements around that is part of what, I think, we will achieve in the industry development fund to which I referred earlier—the industry development plan that has been built collaboratively with the sector.

We see ourselves as trying to move away from just managing a funded service system to try to manage the totality of effort being made whether it is coming from government funding or not. That is probably a long-winded way of saying, Chair, that we can do more. I do not deny that. We are doing some, but the issue goes beyond just management of the government-funded system. Again, if you come back to one of the reasons that it is useful to use that expression about helping a person with a disability and their family get a good life, a better life, the key to that is going to be how the community more generally gets involved. For us to be able to encourage non-government sector players to leverage community resources into the service delivery, not just make it about what we are funding them to do, is a critical part of being able to change the community.

CHAIR: In leveraging that social capital, as you call it, once you have done that I assume that the Government, the department, will have the role of monitoring the overall need—government or non-government—in the community for quality and grievance procedures.

Mr MOORE: We will not escape that responsibility.

CHAIR: Okay. So in determining the definition of "need" it does apply to all people in the State irrespective of whether they are serviced by the government or by non-government?

Mr MOORE: Yes.

CHAIR: You have the responsibility of monitoring that?

Mr MOORE: That would be the way I understand my charter at the moment.

CHAIR: Particularly the quality of that service?

Mr MOORE: Absolutely.

The Hon. TREVOR KHAN: Mr Moore, I do not mean to be rude but there are four people at the table. The Committee has spent an hour speaking to you. I wonder why we have four people present. Ms McAlpine, you are a deputy director general of the department, what do you do?

Ms McALPINE: I am responsible for our supported accommodation service; that is, the government group homes, funding to the non-government sector supported accommodation and our large residential centres. The Home Care Service of New South Wales reports through me as does Aboriginal Home Care. I am responsible for the Office of the Senior Practitioner, where we have our integrated services program. That is a cross-government initiative that has a joint committee with us, Health and Housing. We provide the services for people with significant challenging behaviours that have challenged various agencies to support them. Not all of those people have an intellectual disability or a disability that would make them eligible for our services. It covers people with mental illness, drug and alcohol issues.

That was recurrently funded after a three-year pilot. It has significant success in changing people's lives and enabling them to reconnect with their families and their communities and to live a life that kept them out of the criminal justice system and kept them away from police and emergency health departments. The Office of the Senior Practitioner has our community justice program, which is currently providing services to about 143 people with intellectual disability who have exited in the criminal justice system or the juvenile justice system. Primarily under this we provided accommodation services, case management and clinical support services to address the aspects of their behaviour that caused the offending to begin.

The Hon. TREVOR KHAN: Right.

Ms McALPINE: And that is not all that I do.

The Hon. TREVOR KHAN: No, I am sure it is not. In that division of the department, how many people report to you?

Ms McALPINE: Because I have the supported accommodation and the Home Care Service of New South Wales, it is a significant slice of people who report to me.

The Hon. HELEN WESTWOOD: Chair, I request members to identify themselves before they speak, for the benefit of the blind and visually impaired people in the gallery.

CHAIR: Yes.

The Hon. TREVOR KHAN: I am Trevor Khan, a member of The Nationals. On the issue of supported accommodation, we have spoken in various terms about the shortcomings in the assessment of the unmet need in the supported accommodation area. Would you agree with that?

Ms McALPINE: It is very difficult for us. We know of over 1,700 people who have come forward and said they would like accommodation immediately. Over 700 would like it really quickly, and 1,000 would like it sometime in the future. How many more than that? We do not know.

The Hon. TREVOR KHAN: Let us deal with those who have already put up their hand. Do you keep some sort of record as to how long those who are looking for urgent assistance or accommodation have to wait, on average? Further, do you collect any data on that on a region-by-region basis as opposed to an overall State basis?

Ms McALPINE: Yes, we have a client information system, which is a statewide system, and you can read the reports region by region. Those 1,700 people who have expressed a need for accommodation are all listed on that data system. We can generate reports by region for that by age, by age of the carers, by length of time since the request. If you have a really immediate need, and you need something this weekend, we have an emergency response program. Currently about 150 people are being supported through emergency response. For some of those people, but not all, it is an interim accommodation placement until we can find permanent accommodation placement. However, a small number of that 150 might have a different response. It might be a period of immediate respite that is required while a parent has an operation and before they can begin caring for that family member. While the bulk have no other accommodation option, it is not the exclusive domain of the 150.

The Hon. TREVOR KHAN: I do not want to cut you off, but go back to the 1,700 and your ability to divide that by region, et cetera. Are you able to provide that data to the Committee within a reasonable time?

Ms McALPINE: Yes.

The Hon. TREVOR KHAN: Within 14 days?

Ms McALPINE: Yes.

The Hon. TREVOR KHAN: You talked about being able to segment it by age and other criteria. Are you able to provide that within 14 days?

Ms McALPINE: Yes.

Mr MOORE: Might I interrupt: You will find some of that information is already available in our submission.

The Hon. TREVOR KHAN: Yes, I am sure.

Mr MOORE: We have no qualms in providing a little extra, which I think would explain the length of waiting time on the list. I want to put on the record that we may disappoint you somewhat in that because the list is only growing into being a credible list. We have been building it up. Only in the last six months we have had the right policy settings in terms of definitions and so on. It is being done on region-based information to get a consistent document. We will do the best we can.

The Hon. TREVOR KHAN: This is not a criticism. I am trying to work out, in truth from what has already been said, why these things are being identified only now, within the past six or 12 months? These issues have been alive for many years, if not decades. Why is it now we seem to be coming to a flourishing new age of identification?

Mr MOORE: What you have to see in the broader management of specialist disability services is that we have moved from being reactive to beginning to become proactive. Over the period until this dividing line in policy settings within New South Wales, called Stronger Together, it was always a very reactive response. Sometimes there were really good initiatives, such as the introduction of the post-school programs and so on, that were not just simply reactive to pressure, but had a policy direction. Most of the responses in the disability stage had been of the ilk of reacting to pressure at the moment. With Stronger Together we acquired a more systemic response. The Government set some longer objectives that we were required to manage against. Instead of wanting to collect the people who were most in need right here, right now, let us provide a response to that. In one year we provided 197 support packages to people, because 197 people we explicitly identified.

That was incredibly reactive, because they had to get to the point of crisis before we make the response. We have now begun to move the other way. In the early years of Stronger Together the implementation was about getting the resources out the door. The choice that we made in rolling out the $1.3 billion, that was part of Stronger Together, in the first five years was to get capacity on the ground, to do some of the major policy things. It was the second step. The first step was that we could not argue that there was a need for more supported accommodation. We could not argue that kids were leaving the DOCS system who needed to have supported accommodation. We could not argue that we needed more respite. So we did need to go on and do a big policy analysis and fine tune, to be able to make the initial response.

As we are now heading towards the second five years, we are doing a lot of policy refinement and tidying up and moving ourselves to being able to administer the system more systemically. As a head bureaucrat, the thing that is import in the administration of Ageing, Disability and Home Care is that we are a very lean operation. When you look at some of the public sector benchmarks about our overheads you see that they are low.

The Hon. TREVOR KHAN: Could you repeat that last sentence, please?

Mr MOORE: If you look at our non-funded overheads on delivery, in terms of some benchmarks across public sectors, we come out low.

The Hon. TREVOR KHAN: And those benchmarks are available in some tabulated form?

Mr MOORE: I am sure I can provide some that would show that.

The Hon. TREVOR KHAN: Within 14 days?

Mr MOORE: Yes.

The Hon. TREVOR KHAN: Thank you.

Mr MOORE: That is something we are proud of, but it does have certain consequences. It means that our capability to be able to do some of the policy work on the higher level of refinement of our settings takes time. We spend most of our time pumping out services to people.

The Hon. TREVOR KHAN: Ms Murray, what do you do?

Ms MURRAY: I manage the community-based services other than respite. The Home and Community Care Program comes under my responsibility. Other community-based services such as the day programs and the post-school programs, therapeutic, community-support teams—which we run directly—are also under my responsibility. I am also responsible for the intake and assessment process for families and people with a disability—also the relationship with the non-government sector.

The Hon. TREVOR KHAN: Dealing with the intake and assessment process, do you keep any data on how long it takes from the notification or request for intake or assessment until the actual assessment process is undertaken?

Ms MURRAY: Yes, we do.

The Hon. TREVOR KHAN: Are you able to give an indication as to how long that takes?

Ms MURRAY: It varies. I probably should take that as a question on notice as to the specifics, to be accurate, but we are talking about 12 weeks in most cases.

The Hon. TREVOR KHAN: Do you have that data on a regional basis? Ms New nods.

Ms MURRAY: Yes.

The Hon. TREVOR KHAN: Are you able to segment it into different areas, for instance, age groups and range of disabilities?

Ms MURRAY: Yes, more age than disability because, in a sense, we may still be sorting out what the needs are.

Mr MOORE: If you are in a position to turn to page 54 of our submission you will see for one service type, our therapy-type services, disaggregation about the times and services requested by age group. We are more than happy to get you the additional disaggregations across as many of our program types as we can. I also draw your attention to the fact that what we will be giving you is a picture of the government-only service provisions. We do not have access to this sort of data for individual non-government organisations.

Ms MURRAY: I can talk a little bit more about the impact of that, for example, on our community support teams, which provide therapy services, behaviour support services and case management services. We have about 28,000 people a year who receive those services. On a register for request for services, about 8,000 people do not currently have a service. Half of those 8,000 people are receiving another type of service, probably from our community support teams. Then another 35 per cent have completed a service within the last three months. People may request a number of things when they request a service. So they may be waiting for some but receiving others. The vast majority of people have received a service. Then there is another 10 per cent who have received a service within the last three months. If you count all that, you have a substantive number of people who have received some sort of service but may be waiting for a different one. There are about 780 people who have not received any service at all. So it is a much smaller number. Of that number, about half have waited less than three months. Of that other half, they wait equally between under six months and under 12 months or over 12 months. That gives you some idea of the numbers we are talking about and the times they have to wait.

CHAIR: The figures on page 54 do not include the 460-odd non-government organisations?

Ms MURRAY: That is right.

CHAIR: What percentage of the overall figure is non-government organisation services and government services?

Ms MURRAY: Overall it is about half and half.

CHAIR: It is 50-50?

Ms MURRAY: Yes, 50-50.

CHAIR: What effect will it have—

Ms MURRAY: Can I interrupt you, Chair, to say it depends on the service type? For example, most of the case management services are provided by ADHC direct, but the non-government sector provides a large amount of therapy services. So it depends on which particular service you are talking about. Overall, it is about half and half.

CHAIR: The figures are a lot more complex than as shown on page 54?

Mr MOORE: Yes.

Ms MURRAY: The figures on page 54 relate directly to our community support teams, which are the services we provide directly.

CHAIR: As to the recent National Health and Hospitals Network Agreement, which establishes the Commonwealth taking over funding for your area, Ms Murray, am I right in saying—

Ms MURRAY: Yes, that is right.

CHAIR: —and taking over, as I understand, policy, management and delivery responsibility for a national aged care system, what effect will that have in terms of any function of the State in monitoring grievance procedures and all those issues related to delivery?

Ms MURRAY: The component of our service system that the Commonwealth is taking back is the Home and Community Care Program, which provides services for people with a disability and frail older people. The way in which the Home and Community Care national changes are going to go is that the State will be responsible for people under 65 and under 50 if you are an Aboriginal person and that the Commonwealth will be responsible for services for people over 65 and over 50 for an Aboriginal person. It is really about the Home and Community Care Program, which is a separate program from our disability program. Our current disability program, which is funded by the State, remains within our purview and our responsibility. So we are talking specifically about the HACC Program. I am happy to talk a little bit about it.

CHAIR: As I understand it, the $500 million is funded through HACC?

Mr MOORE: If I can elaborate on what we have been saying, I am not sure if this is confusing you. In relation to the HACC Program, which is $550 million that comes into Ageing, Disability and Home Care, $170 million of it goes to the home care services for New South Wales, which goes to this Deputy Director General here. The remainder of it goes to the non-government organisations through this Deputy Director General over here. The overall program responsibility for HACC sits here. It is in that context where the specific question you are asking about, monitoring and so on with respect to the Commonwealth proposition—which has been agreed to by the New South Wales Government—is that the New South Wales Government's position, however it is implemented, does not translate to a duplication of reporting and monitoring arrangements. One of the very significant negotiation points to be had with the Commonwealth is that if they take their money, so to speak, for people over 65 and start funding organisations for that we will be funding the same organisations for the under 65. We have to find an arrangement whereby we do not end up causing those organisations to have two separate monitoring processes and two separate reporting processes. That has a lot of negotiation left in it before we reach a position on that.

CHAIR: We need more information in order to understand what we have been talking about. I am confused by it.

The Hon. HELEN WESTWOOD: I was a HACC worker many years ago in the Macarthur region in its early stages. I have seen the development of that program and I believe it has paid huge benefits to the community, certainly for people with disabilities who remain living at home. Looking at the largest figures on page 54, which relate to 0 to 5 years and 6 to 15 years, do we know what level of disability those children have? Are we talking mild to moderate or severe to profound? I ask that question because we are all very well aware of the importance of early intervention in improving quality of life and outcomes for children with a disability. Do you know that detail?

Ms MURRAY: I can talk a little bit about the policy framework, particularly in relation to children under five or six in terms of the policy applying for preschool-age children. For our community support teams, generally speaking, for adults and older children there is an expectation that you will have an intellectual disability. But for children under six it is a much softer definition in terms of allowing broader access and there is a requirement that you have a developmental delay and some sort of functional impairment. It means that the gate is much wider, particularly as some children by definition may have developmental delay for a period of time but may catch up. It means that you are able to provide support to a broader range of children to be able to meet their needs, rather than having to do tight and definite assessments about people's long-term capability at such a young age. For young children there is a broader definition of developmental disability, but by the time they are six and head to school there is usually an expectation that they will have an intellectual disability. If you want to be technical about it, an IQ of 75 as the standard deviation will remain.

The Hon. HELEN WESTWOOD: Are you concerned that there are children in these categories who are receiving no other services and have been diagnosed as having a disability?

Mr MOORE: Yes. What this table will not be able to do for you—and given your interest I am happy to see if we can get an expanded table—as to the question of the prioritisation of this person who has requested a service is reflect the length of waiting. I am not saying they are necessarily all like this but someone with a relatively mild disability, the intervention is probably as equally appropriate delivered out of the general health therapy system. There is no disaggregation of that in terms of our data that I can show you. There is an example of need. You can pack and unpack this in some detail. I am happy to have that brought to you.

The Hon. HELEN WESTWOOD: That would be useful.

Ms MURRAY: If I can add to that, when children or people with a disability and their families make a request for services, there is always an assessment of the requirement for immediate response or not. It is quite likely that the people who are waiting longest have other services or their need is considered not as high as other people's. There is a definite assessment to determine how quickly people should respond and be given priority.

The Hon. TREVOR KHAN: In that regard I am particularly interested in the 0 to 5 years category and the need for speedy early intervention, which I believe is where Ms Westwood was going as well. Do I take it you can unpack that 0 to 5 years category to identify those children who have not received any form of initial assessment or support from those receiving ongoing support and asking for additional assessment?

Mr MOORE: Yes. We can unpack it for you and I will endeavour to get for you a couple of de-identified illustrative examples of people who are in categories of waiting a long time.

The Hon. TREVOR KHAN: Can it also be unpacked in regions? I am from the bush, so we will accept that there are regions outside Sydney. Do I take it that Sydney is not one amorphous mass and there are various regions within Sydney?

Mr MOORE: Sydney breaks into two, basically south and north.

The Hon. TREVOR KHAN: There is no western Sydney region? It is essentially along the Parramatta River?

Mr MOORE: Something like that, yes. Again, I cannot give you a strong guarantee on this but we do have some regional zones that we use for some planning purposes and some delivery service purposes. I am happy to try to unpack that for you a little bit further. We do know in a number of areas that we are particularly low in service supply. When we get to south-western Sydney, that has been a major focus for supported accommodation. For us to get supported accommodation space we have deliberately gone and put significant resources into south-western Sydney over the last couple of years because it has been the area where relative to the general population data we could tell it was underdone, as was the Northern Rivers region of far north New South Wales.

The Hon. TREVOR KHAN: Again concentrating on that 0 to 5 years category, do I take it there will be a significant percentage of parents who are seeking assistance who are from various regions and non-English-speaking backgrounds?

Ms MURRAY: Yes, that is correct, particularly in some regions, obviously.

The Hon. TREVOR KHAN: In terms of those parents requesting assistance/assessment, what is the capacity, for instance, for a paediatric psychologist who may have seen the child already to make the request for assessment or support independent of the parents or conjoined with the parents? Is there such a capacity?

Ms MURRAY: Yes, in relation to the issue of need of a family and also the idea of trying to bring to bear the information that is available already, so that you do not have to provide additional assessment. If there is information available that is relevant to the particular circumstances that always would be taken into account in a holistic and multidisciplinary way.

The Hon. TREVOR KHAN: Do I take it if the clinical psychologist or paediatric psychologist makes an assessment with the parents that would expedite the assessment process?

Ms MURRAY: Yes, if I understand the question correctly. If there is information already available that is relevant to decisions being made about the types of support then that should be taken into account, unless you are talking about a specific case. In general, that information should be taken into account.

The Hon. TREVOR KHAN: I take it your data would not be able to distinguish those where a paediatric psychologist or the like is provided—your data would not dig that deep.

Mr MOORE: No. That would not be held as a data field. There might be some case notes in the electronic system but you would not be able to pull them out.

The Hon. GREG DONNELLY: Mr Moore, page 13 of your submission refers to numbers—I am sorry to return to this issue but it is important to understand what we are talking about. In your submission this morning you said you understood there were about 400,000 people in New South Wales with severe or profound disabilities but in the submission the number in the second paragraph is approximately 450,000. Is it your understanding that 450,000 is the figure?

Mr MOORE: The 450,000 figure is I think a reference to our extrapolation from the 2003 data, where the figure was about 400,000. I think that would be our best estimate of the current number.

The Hon. GREG DONNELLY: So we are talking about 450,000. In terms of the number of people ADHC deals with, you also said in your oral submission this morning that you have direct contact with between 50,000 and 60,000.

Mr MOORE: Yes, in terms of the specialist disability system, but you have to remember that we walk this sometimes confusing line between what comes under specialist disability and what comes under the Home and Community Care program. There are people who overlap those two. Our best extrapolation of how many people we help in the specialist disability system at any one point in time is around 50,000, and with the flow through the year you get close to 60,000.

The Hon. GREG DONNELLY: For argument's sake let us call it 50,000. There are 400,000 people in New South Wales with a severe or profound disability and who are not interfacing with ADHC. Do you have any idea how many are interfacing with any of the 460 non-government providers? Is there a rough macro number we can work with?

Mr MOORE: The 50,000 quoted is both government and non-government. Speaking loosely about the numbers, that means there are 400,000 people with a severe or profound disability we are not providing a service to at any point in time. You might ask what that gap translates to—

The Hon. GREG DONNELLY: That is exactly what I am trying to ascertain.

Mr MOORE: In rough terms, half the people who have a severe or profound disability are aged over 65. That is just a reflection of the fact that your disabilities arrive or are exacerbated as you get older. On page 14 you start to get a sense that the single biggest block of the 450,000 are people who have long-term health conditions.

The Hon. GREG DONNELLY: Are we going with 400,000 or 450,000? We are talking about 400,000 because we are taking out the 50,000, are we not?

Mr MOORE: Figure (1) on page 14 is for the whole 450,000. In 2003 the single biggest number was those with a long-term health condition. In addition to what we do in our specialist disability system there is what the health system does and that is why that long-term health condition figure is important. Since we are dealing with all people over 65, the residential aged care system is a very significant supplier of services and support in this space. There is also the fact that a large group of people have a physical disability as opposed to an intellectual disability and there are other sorts of service system responses that come from things such as insurance compensation and occupational health and safety. That is not to say that they satisfy the full level of need, but it is more than just a matter of looking at the 450,000 figure and saying that ADHC's programs should be the sole source of response. There are a range of service systems that provide support to people. The simplest one to understand is residential aged care, and I think the comparable number is probably another 50,000. In rough terms that is what I would say.

The Hon. GREG DONNELLY: There are 460 identified non-government disabled support organisations operating in this State and they are specialist providers. Can you explain to us precisely what specialist disability services ADHC provides?

Mr MOORE: We provide services in supported accommodation in community settings, which is predominantly a group home network that provides support for people in large residential settings. We continue to operate 13 large residential centres in New South Wales. We provide therapy services and behaviour support and behaviour intervention services. We also provide case management services. We would not be unique in any of those services but we tend to have some specialisations in terms of some complex and challenging clients and some specialist health care arrangements. In addition we run the Home Care Service of New South Wales. We provide some high-level support in advising on specialist behaviour intervention. We are not actually doing the intervention but are providing advice to the people making the intervention. As Ethel McAlpine mentioned, there are things such as our integrated services project, which ranges beyond the specialist disability into picking up people who might appropriately be dealt with in part through Mental Health or Housing or the criminal justice system, but they do not fit neatly into one or the other and we have stepped in to pick up that patch in a collaborative way with other parts of government.

The Hon. GREG DONNELLY: I understand the Productivity Commission is currently conducting an inquiry into a national disability long-term care and support scheme. Can you briefly explain what a national disability long-term care and support scheme refers to and the possible implications such a scheme would have on the funding and delivery of disability services in the State?

Mr MOORE: The Productivity Commission has not proposed a particular form at this stage and it could range from a really simple levy—I am not an expert on all the ins and outs—similar to the Medicare levy arrangement through to a highly specific insurance scheme not unlike what we have in New South Wales with the Lifetime Care and Support Authority where an insurance levy is paid for specific purposes and if the event arises, in this case presumably disability at a certain level, the costs of care or some costs of care will be paid out of the scheme. My understanding is the Productivity Commission is looking at the various models that might be put in place. What implications would have that for us? Depending on the model, it could be very far reaching. If a significant new player is providing support to a particularly large group of people with a disability that would cause us to reconfigure how we operate both in terms of who we cover and what sorts of supports we might provide. If you are funding catastrophic levels of disability or injury, similar to the Lifetime Care and Support Authority of New South Wales, you are going to have a group of people who do not meet that threshold. You have to make sure you intervene so that their condition and their circumstances in the community do not degenerate to the point where they need that level of support.

It could have a significant impact on how we operate but at the same time what has driven a number of people, if you listen to them talk about the Productivity Commission inquiry, is the realisation that comes from what I was telling you earlier about the longevity of people with a disability. The good news about people with a disability is they are living longer. That places an additional impost upon carers. If you are living longer then your parents are also living longer and will get older as they care for you. There will be a substantially growing demand for funding. In the New South Wales context, we in ADHC have been growing much faster than certainly the rest of the budget in total and for the last four years we have grown faster than the health system. That is unsustainable without some alternative revenue sources.

The Hon. GREG DONNELLY: Is it something like double-digit growth?

Mr MOORE: Not yet, but depending on how things pan out I think we could see very significant growth in demand for funding and without an alternative revenue source the impact would be unsustainable on the State Government's budget.

The Hon. GREG DONNELLY: What is the planned reporting date for the Productivity Commission's inquiry?

Mr MOORE: The middle of next year.

(Short adjournment)

The Hon. HELEN WESTWOOD: One of the terms of reference specifically relates to complaints handling. Would you describe to the Committee the complaints handling mechanisms that are in place in the department? What sort of complaints does it receive? Does it receive complaints not only about call-in service but also the perennial question of unmet need?

Mr MOORE: Just as a preamble I would say that I do not think that we do well enough with complaints handling. I do not think that we get near as many complaints through our formal complaints mechanism as we would want. There is only one area of our business where there is a significant body of complaint and that is in the home care service of New South Wales. I do not think that is a reflection necessarily of us doing less work in other parts of our organisation but it is just that they are much more efficient at counting complaints as complaints, as per my earlier points I was making about the effort that we are putting into our moving into more systemic management away from just simply rolling out services.

Complaints is an area that we are only at the beginning of trying to build a much more effective way of trying to manage them. Generally we are not getting complaints that we count as complaints about unmet need and that is not because no-one is complaining but our complaints are currently counted through a formal complaints process where there is a way to lodge a complaint with us and then we will handle that complaint on its merits and endeavour to resolve it. To that end I do not think people use complaints simply to register concerns about them, such as unmet need.

CHAIR: When you say "unmet need" and you are talking about a service that is not adequately delivered, is that not part of an unmet need or do you not use that definition?

The Hon. HELEN WESTWOOD: I am interested in the model of complaints handling mechanism model that is used and I assume a significant part of which would be about quality or poor quality of service, insufficient service. I think the other part of my question has been answered which was if you also receive complaints about unmet need, that is, when someone wants respite services or that supported accommodation is not available where do they go to register that complaint? Does the department record that complaint and use that data? I think you have answered the second part of my question.

Mr MOORE: I was using "unmet need" solely in terms of someone not getting a service and wanting a service and getting a service but not a good enough service.

CHAIR: So an inadequate service is not unmet need?

Mr MOORE: No, absolutely not. I do not say that at all. I was using that expression in answering that question referring solely to the circumstance where the need is not being met by us at all. I suspect if a person does not complain very often to us about a service they are not getting, as opposed to a complaint about a service that they have got.

CHAIR: If I need 20 hours of service and I get two hours, is that a met need or an unmet need?

Mr MOORE: That would be an unmet need.

CHAIR: That is where I am confused about the definition of "unmet need".

The Hon. HELEN WESTWOOD: The purpose of my question is to understand whether there is an opportunity for people with a disability or parents or carers of children with a disability to lodge a complaint if they are not getting a service that they need, as opposed to the quality of service, that is, we know with health care service that people complain about what they believe is poor quality, unprofessional treatment versus not being able to get a service. We have talked a lot about unmet need and the capacity of the department and the sector to really quantify that. I want to know whether the complaints mechanism of the department record that and whether it receives any useful data about that. However, I believe that one part of my question has been answered that you do not record it and there is not anywhere for people to go to complain within the department when they are not getting a service that they need.

Mr MOORE: Let me start again. I am saying that there is a complaints mechanism within the department to which anybody can make a complaint. I do not believe that people who are not receiving a service and need one are utilising the complaints mechanism to give us any genuine insight into the level of need not being met by not providing a service at all. I do think that we know, and it is one of the appendices to the submission that we provided, we look at our formal complaints data and the thing that is obvious is that the only area where we have got sufficient complaints reads to be something that is informative for us as management is in the home care space. We can clearly see that it is in terms of the level and standard of service delivery that is the core of the complaints. There is a wide range of complaint issues but they are the ones that make up the bulk of the complaints that people do make about the home care service.

We put those complaints in the context where we do biennial surveys of client satisfaction of the home care service of New South Wales. It is done by an independent group so we do not conduct it ourselves. We get client satisfaction in the levels of 95 per cent plus in those surveys. Yes, there are about 600 complaints that we received in 2009, 662 to be precise, about the home care service and that has to sit alongside a very positive overall relationship to the home care service of those clients, but we do not believe that we get it right. I think that that number of complaints when you are dealing with 55,000 of the number of clients of Home Care Service of New South Wales that with a 95 per cent to 97 per cent satisfaction rate is probably a good indication of what is not working for individuals. We have nothing like that for the rest of our service system and we are endeavouring to work out what is the best way to try to gather that information. My fear is that that information is not going to be about the people not getting services.

The Hon. HELEN WESTWOOD: If a receiver of the service wants to complain about the quality of it—for example, if they are in a supported accommodation service not run by a non-government organisation but funded by the department and they felt that the quality of that service was less than the minimum standard—how would they go about making a complaint about that and having that rectified?

Mr MOORE: First and foremost, they would be expected to approach the organisation providing services to them and use the complaints means that that organisation provides. If they were to come to us directly we would encourage them to go to the organisation in the first instance. Were they to retain a concern then they are welcome to bring that complaint to us and we would then deal with that in terms particularly of how effective or not the complaint had been handled by the non-government organisation.

CHAIR: Is that irrespective of whether the funding comes from Federal or State?

Mr MOORE: At the moment the sorts of services that we would deal with—whether the money is coming from the Federal or State it goes through the State system. We do not disaggregate between Commonwealth funded—that is within the specialist disability arrangement because, as Ms McAlpine was pointing out to me, there are other parts of the service system in the broader context, like employment services, business services, some form of respite, that the Commonwealth funds direct, which only adds to the confusion that people experience when they are trying to work their way through the service system. But if a complaint about a non-government organisation was in terms of their business services then we would be going back to the person saying this is not something that we have any responsibility for and we would point them in the right direction to move that on.

In addition to the ability to utilise our complaints system—which I will again say I do not think is near well enough utilised—people with a disability and their family have access to the Ombudsman and the New South Wales Ombudsman is, for us, a very important part of the process of being able to run a system that is seen as being independent and effective because we will remain the funder of a service that person is complaining about. The Ombudsman provides us with a vehicle whereby someone independent of all of us is forming a view about the complaint. I have no hesitation in encouraging anybody who is concerned about a government service that is being provided by the government or by a non-government organisation to then take their concerns to the Ombudsman and the Ombudsman has the ability to deal with that. We find ourselves working very hard to address any concerns that the Ombudsman gives rise to.

I also point out that we have, through the Ombudsman, an official visitors scheme for some parts of the specialist disability services, which provides directly to the Ombudsman people who go and independently visit the services and form their own views of what is going on in a particular service and report that back up through the Ombudsman and also to regional management to address actions that are either in their operation or in the funded services operation. I do not think it is perfect; I think that a lot more effort needs to be placed into this space, but there are a number of vehicles that are available for people to have their service quality tested or to complain about it and have an independent treatment of it.

The Hon. HELEN WESTWOOD: Does the funding agreement that the department has with non-government organisations make a complaints handling mechanism a requirement of that funding? If so, does the department review the effectiveness of those complaints handling mechanisms within non-government organisations?

Mr MOORE: We require all non-government organisations, through our funding agreement, to comply with disability standards, one of which is about complaints and disputes resolution. So through that vehicle we place upon them an obligation to maintain a complaints handling process and to handle disputes appropriately. The first port of call for somebody to come to us is we would be going back to the non-government organisation to understand whether or not the complaints handling process had been done well enough.

The Hon. HELEN WESTWOOD: Is there some way in which the department is monitoring those complaints handling mechanisms within non-government organisations to satisfy yourselves that they are meeting the standard? It is one thing to have a complaint but if there is no appropriate response to that then really it is fairly useless. Is there a monitoring of those mechanisms?

Mr MOORE: We have certain compliance requirements that are placed on non-government organisations in terms of the attestations that they have to give us at the board level about their compliance with disability service standards. We have been through virtually all non-government organisations over the last three years with a tool that has been used—the integrated monitoring framework is the name for the tool—to test each non-government organisation's compliance against, among other things, governance and standards and so on, and we are moving into a new regime where we have got a much more risk-focused approach to who we would be wanting to monitor and check and test, and we want to do that in conjunction with the industry development processes that we are trying to put in place where we are trying not to end up with a very heavy overhead of monitoring as opposed to building the capability of non-government organisations to better govern themselves.

At a certain level if you have got a non-government organisation that you are working with you would expect the board itself to want to know the same sorts of questions that you are raising, and for us the next step in industry development is to try and build a calibre of self-governance within the sector. That then gives us the ability to be even firmer where instances come up where there have been inappropriate responses, where there have been system failures within the non-government organisations. It gives us an ability to deal with them, I think, on a much more firmly based footing than what we have if we are trying to take on the total responsibility of judging for ourselves whether everything is being done correctly, because short of a very significant workforce it would not be possible for us to be convinced year in year out that every one of those non-government organisations—which, when you go across both HACC and disability, adds up to be around 900 the workforce that you would need to do that. I think you would be far better off spending that on other things, including front-line services.

A clear problem that we need to solve is whether this is a service system that is delivering quality services that are appropriate to clients and meeting their needs on their terms. I do not think that needs to have as its main delivery tool a strong, ubiquitous, spread-everywhere form of monitoring service. That is not to say we would not need it, but what I am hoping is that we can get to a very strong but small group who when we do need to intervene we can intervene firmly. But we have done everything to position ourselves in terms of the non-government sector to say, "We have given you every chance, every latitude and now this is the situation we are in". That gives us a better chance to respond with a firm hand if we need to. I do not deny that you would need to with such a large number of services. Not everything goes well all the time; it does not go well with us all the time. But I think that we also are dealing with a very interested group of people who are primarily driven by doing good things for people and that we need to respond to that in a positive way, not in an upfront overly regulatory way.

CHAIR: However, in not doing it in an overly regulatory way I am assuming that the department would not want to vacate the role—it is part of their role—and in terms of the user exerting their rights and their charter of rights and using the facilities, be it government or non-government, in the most effective, efficient way, they need to be able to exercise their rights and in exercising their rights they need the ability to access the facilities that enable them to ensure that their rights and the quality of the service that has been provided can be monitored and properly assessed—not just have a situation where we vacate the field and say, "Now you have got rights, go forth and use them somehow". Am I right or wrong?

Mr MOORE: In terms of how you would administer the system, I have to concur with what you have said. We will not, because I do not think we can, vacate this space. I do not think you could run a system where people are getting what they want, choosing the services that they want, if you just were to go to the extreme end of how you may step away from the process.

CHAIR: Let us take an attendant care program.

Mr MOORE: The person still needs to have sufficient assurance that what they are getting is what they are entitled to: the way in which the personal care is being delivered, they can have a high degree of comfort, that this is the standard of personal care it should be at. I do not believe that with both the nature and number of individuals we are supporting that you could do that without a lot of activity by the agency in working, I hope collaboratively, with the sector but in being able to gain sufficient information so that people have confidence in the standards they are delivering. I think the best example that sharpens this one is in the respite area. If what you had was a respite service where, from the moment the parent dropped off their family member to when they collected them they worried about what was happening to them intensely, where is the respite effect? That really just dissipates. I do not think you can rekindle that respite effect by saying, "Well, it's now up to the family member to go and sort it all out" when it is all being done behind closed doors in a perfectly good way. You have to have some means by which they can get that assurance.

CHAIR: From what you said earlier I understood that we have gone, I would assume rightly, from a reactive system to a proactive one where we are trying to ensure that we are across all the requirements of unmet need or understanding the unmet need, with the proactive process involving monitoring and ensuring that people are receiving the quality of service they are after. In one respect we are saying that we need to do more proactively to understand the need yet when it comes to monitoring a grievance process or having a grievance process that enables users to exercise the rights they have supposedly under a charter of rights to enable them to access quality care there seems to be a bit of a softening in the approach.

Mr MOORE: If that is what you are taking from what I am saying then I am misleading you. I do not think we are talking about a softening of approach; I think we are talking about how can we get a more effective approach and how can we get an approach that does not just simply resource outsiders to come and pressure NGOs to behave in certain ways and check whether they are behaving in certain ways. You will always need some of that, but can you get more of that effect by helping NGOs build their own capability to better monitor what it is they are doing? What would it take to make sure that NGO boards are well aware of the level of complaints that are coming into their organisation? What are NGO boards doing about that? I would like to get a world where that is a significant part of our strategy for giving people confidence because then they are not just looking to my agency as to how it is monitoring.

CHAIR: But you are monitoring also unmet need: on one side the user and on the other side the provider who would be saying to you that a lot of the unmet need is because we have not got adequate funding. The monitoring goes across the board, does it not?

Mr MOORE: Yes.

CHAIR: You are asking to proactively work out what unmet need is. In answer to an earlier question, previously we were not up to speed with unmet need, but with Stronger Together from 2006 we have been looking at how to better monitor the unmet need?

Mr MOORE: Yes. I make a distinction between monitoring about the volume of service that is required—that is the discussion about unmet need—and then for whatever level of service is being funded, is that service being delivered at an appropriate level in terms of quality and in terms of ensuring that a person gets what it is we are paying for them to get, and also ensuring that they are getting something with a degree of confidence that they need for that service to be effective. There was just my story about respite on the one hand and on the other somebody who is in the hands of another individual organisation for personal care requirements.

CHAIR: Could you reassure us that on page 54 of your report we are only really seeing one part of the story—the Government side of the funding? There are some 600 service providers and 460 NGOs. That does not appear in the picture?

Mr MOORE: I was referring the member to the page 54 table just as an illustration as to how we could decipher that data. In the case of our therapy services, we do not hold data on all therapy services delivered by all organisations. There is a question as to whether we ever would. But when you move to the other end of the spectrum of interventions, which is the specialist accommodation support system, we do hold data on the vacancies within the government and non-government service. We are building a broader array of data and understanding across the service system. I would see the pathway we are on as not one of retreating and retracting but of building and getting more information. I am sure you will hear what the industry itself has to say later, but my view is that the industry itself would be craving more data or information on service delivery and who is delivering what to enable it to make its own planning decisions and organisational things. We have a shared purpose in building better information. Our problem is that we have nothing—a lot of space that we need to build systems. We need to build the capability of organisations to provide data. It is not a simple thing for them to do. We need to work collaboratively to get there rather than trying to engineer it upfront and then demand that they meet our requirements.

The Hon. MARIE FICARRA: I do not want to get bogged down with complaint handling but just on simple logistics I understood you to say that complaints reporting seems to be a little more efficient and effective in the home care delivery sector as opposed to the overall departmental approach. You then talked about the formal process of lodging a complaint. If I want to make a complaint not about home care but some other service provided by the department, how onerous is it to lodge that complaint? What do I have to do logistically?

Mr MOORE: Logistically, you need to write to the department saying that you have a complaint. It can be as simple as that. Our website makes available information about who you can write to and how you can do it. Our thinking is that it could be a lot better, it could be a lot clearer, but logistically it is not hard to start the process.

The Hon. MARIE FICARRA: Do you believe it is user friendly enough or are you aiming to make some improvements?

Mr MOORE: I think the biggest problem is not so much the user friendliness of the system, but I stand to be corrected by actual users of that; it is literally the awareness of the process. It gets particularly hard to rely upon that when you are talking about people who are not getting the service. How do they know about that? Some people are very good, they do find out about these things, but not very many.

The Hon. MARIE FICARRA: The level of awareness of users could be improved?

Mr MOORE: Yes.

The Hon. MARIE FICARRA: Therefore, the complaints handling procedure may not be totally accurate because people do not know about it or it is too difficult, or they do not know how to access it?

Mr MOORE: If you look at appendix 12 at some point you will see the starkness of the home care service number of complaints compared with the rest. Home care is about managing a specific service, just like an NGO at one level, where some of the questions we were talking about regarding complaints is management of the totality of the system, not just a particular operation. Home care has a longstanding commitment to quality service delivery and always tries to make itself better.

The Hon. MARIE FICARRA: Turning to internal and external program evaluations, how has the department's internal program evaluation been put in place? How do you evaluate whether your services are hitting the mark or where you need to go in the future?

Mr MOORE: Our primary use of evaluation is when we do something new and different, particularly where it is of some degree of significance. We then usually schedule a formal evaluation to test whether we got what we thought we were going to get and could we do it better. One I was referring to earlier in my evidence, which is the transition to work program, the one about the 1,000 to 1,500 people who now have employment, has now just concluded. It was an extensive look at just how it worked from all perspectives. We have a schedule of evaluations that we go through. They target change; was the change effective? We also have, from the perspective of how agencies like us operate, a quite extensive data functionality that goes beyond just simply testing whether we comply with financial statement requirements. It gets into the question of program effectiveness. That is a process that we are enhancing to get much more into the question of whether the things that are operating are delivering what we want the best way we can rather than focusing on changes.

The Hon. MARIE FICARRA: Is that related to the performance indicator frameworks you have working in the department?

Mr MOORE: I will be absolutely frank with you, I think that trying to get performance indicators that work at the level of what you are really trying to achieve is particularly difficult. If you go back to what I was saying earlier in response to some questions about the good life that kept popping up in submissions, if you say that that is what you are really about, then you are talking about a good life for the whole of the life. Performance indicators at the outcome level are very difficult to formulate. You get a lot of surrogates about client satisfaction. I fear client satisfaction indicators because that actually builds incentives into the system for people to suppress expectation in order to increase satisfaction. That would be an incredibly terrible disincentive to introduce into the system. But we have a risk management framework in the department that maps what we think are our key risks. We then have a series of mitigation strategies, which could be rolling out more accommodation, finetuning how we control separation of duties—a range across the whole gamut of operation. That then drives out what we need to check and test. Some of that gets driven out as we need to have a compliance audit, others it will come out as we need a performance audit, and others it will come out as we need an evaluation. I place much more reliance on that framework because I really do not have the comfort in the sorts of indicators that have been developed: the indicators are too long term.

The Hon. MARIE FICARRA: Do you believe the delivery of your department's services has improved since the establishment of that operational performance committee in 2008?

Mr MOORE: Yes. That committee, again, is one of those examples I was telling you about how we are endeavouring to try to get more systemic. It is getting the executive and the regional management of the department together to start focusing on where things on the ground are not going as expected or are going better than expected and trying to harness that into a discussion at the executive level as to what priorities might need to change, be finetuned, and what policies really are not as appropriate as we thought they were.

It is also a key means of ensuring a much more intangible thing, which is important in an agency such as Ageing, Disability and Home Care, where, as I said, we do not have a high overhead; we do not have a high management infrastructure. We are reliant very much on on-the-ground decision-making and we deal with the clientele which is a group of individuals. It has to be tailored as much as possible for the individual. What is the right thing to do with a group home today, with a particular client? That can be guided by policy, but it really needs a lot of on-the-ground nous and decision-making.

What is important in that process is that the higher levels of the devolved management have a very clear understanding of what an organisation is trying to achieve. The operation performance committee plays an important role for me in being able to make sure that the entire upper management team in regional operations is clear about what we are trying to achieve. That can then guide and inform their advice and supervision to the infrastructure under them, so that the people who do the real work make the decision about what to do with a group home and a referral service today. They are independently doing the right thing there and then, but it is fitting within an overall direction that you want to achieve, and that human services will likely operate in. I do not know of a better strategy. The idea that you would pump masses of management into middle management to control does not seem to me to be a recipe to actually get the outcome you want, so you have to embrace the local decision-making and know that you end up with, first, the challenge of making sure people know where you are going, but then you have mechanisms in place to see how things are changing, where people are off track, and how to bring them back on track.

The Hon. MARIE FICARRA: Regarding the evaluation of external agencies, have there ever been cases where you have stopped or reduced funding because of poor service delivery?

Mr MOORE: There have been a few examples where we have re-auspiced, where we have taken a service from one person and moved it to another, taken it from one non-government organisation and given it to another, or where we have the ultimate capabilities, certainly in high-end services like supported accommodation, to take them over ourselves. Tomorrow we will turn up and deliver a service, given a resource base that we have. If we need to, we can do that. I am aware of one instance where we did that about three years ago, where the intervention that was required, given the level of concern that the family members had, was such that, after some discussion with the non-government organisation, the choice was that they basically handed the service over to us. We turned up and started running the service, while looking around to find another non-government organisation to come in later.

We are having qualms about that, but our relationship with the non-government organisation sector is that that is not the premise we operate under. We have no qualms about doing it, but the thing we are struck by is that we do not need to do it very often. Some people say we should do it more often, but you have to also work out how you would do such a thing and what it would take to know when to go in more often. That is a very difficult choice to be made in our system, and the way we have set ourselves is to operate in a much more trusting, engaging way. That was not always the case. I can remember when I turned up in disability eight years ago that that certainly was not the nature of the relationship between the non-government sector and administrators of the department. It has been a long, hard process to get there. When you have 900 providers not all of them are going to be making every one of their clients happy all the time. You have a balancing act as to when you intervene and when you do not.

CHAIR: However, we are heading towards, or we have encompassed, client-centred—

Mr MOORE: Yes.

CHAIR: Therefore, in that environment, if the client is not happy, there is an issue.

Mr MOORE: That is right. I would much rather spend resources building the ability of clients to choose and to be aware and informed, and use that much more as a means for managing service quality and service delivery rather than trying to put it on the other side of clients and checking—not that you do not need that, but I think you would probably get a much better outcome for people with a disability if what you are doing is putting more effort on the side of getting them the information and helping them be empowered to make choices.

CHAIR: But is it more than just what you and I might think? Is that what the department is doing?

Mr MOORE: The department is building to make a substantial policy direction in that space.

CHAIR: You have indicated that there is something like a 125 per cent increase in respite care. Is that since the introduction of Stronger Together?

Mr MOORE: Yes.

CHAIR: A number of submissions we have received find that difficult to understand and have difficulty accessing respite, particularly quality services and particularly in regional and remote areas. Can you quantify what 125 per cent means?

Mr MOORE: In the first four years of Stronger Together, since 1 July 2006, in terms of respite programs we have put out 3,289 under the Stronger Together program. There will also be another tranche of respite that has come under the Disability Assistance Package, which was Commonwealth funding that was pumped into the system through our organisation, targeted predominantly to ageing carers. I do not have that number off the top of my head but I can certainly give you a table that shows the process thus far.

CHAIR: If you could that would be appreciated because I think that is clearly an area that is in some desperate need.

Mr MOORE: I take that as a question, that there is a lot of need for respite. It is a very common theme for people that they would like lots more respite. Respite is critical for people who are hanging on for supported accommodation and do not want to relinquish their family member, but it is also incredibly important for people who wish to be able to remain significant in the life of that person with a disability. We have put a significant chunk into respite but we have also been trying to cover the field, so to speak. Some of what we are doing is trying to invest in the early end more than we have in the past, knowing that if we do not start somewhere our chance of ever being able to make people's lives better is much less.

CHAIR: But I think, as is universally recognised, the contribution that those carers make to the community is invaluable and financially they are worth billions and billions, and the assistance we give to them in respite is fairly important. Is that right?

Mr MOORE: That would be absolutely true. As to the exact quantification of how much they make in financial terms, there are lots of different numbers around. Believe me, it is a significant number. Whichever number you see, if it is not significant it is not accurate. But the thing that is much more important in understanding the role of carers is not just that they are saving us money but the difference in the life of the person with the disability that they make. The person with a disability is now going to live a long life, is going to need to have people who are not unduly burdened by people who are able to help them build their life in the community. The more we have people continuing in those roles in whatever level they can manage, the better the social outcomes we will get. That is the one that the financial analysis misses time and again; it is not just about numbers in this case.

CHAIR: Your submission states that Aboriginal people are twice as likely to have a severe or profound core activity limitation, yet they are far less likely to access formal services. Can you tell us how you are working with Aboriginal communities to improve responsiveness to your programs and services to indigenous communities?

Ms McALPINE: We operate the Aboriginal Home Care Service, which has eight branches across the State and provides personal care, domestic assistance and respite into Aboriginal communities. It largely employs Aboriginal staff, so it provides culturally appropriate services. We found that we were not getting the sorts of referrals into Aboriginal Home Care that we would have anticipated so we started a new assessment system for Aboriginal people, under the **Aboriginal access** and **assessment team.** Under the new assessment system Aboriginal people take the referrals, Aboriginal people go out and see the person and talk with them about what it is they need, and get some appreciation of the environment they are in and how things might work, and then organise with them the link to the local home care branch so that they can get the service. This has enabled us to increase the number of people from Aboriginal communities who are getting Aboriginal home care services.

We do not see the sorts of numbers of Aboriginal people in our disability services. We have tried a number of specific Aboriginal programs. There are Aboriginal community participation programs, there are Aboriginal family support programs, and we have recently reconfigured our Aboriginal program direction area to come up with a pilot project. They are working with three initial communities, one in the southern region, one in western Sydney and one in northern New South Wales, and that will be to take a completely individualised package approach and work with people, asking them what is it they need—and it might not always be the sorts of supports that we might imagine—and then enabling them to be able to have those supports.

We have a flexible respite program, for example, for Aboriginal families in western New South Wales. What they wanted for flexible respite was the ability to take their family member with a disability camping. So we provided a number of camping trailers that are stationed throughout the western region, and Aboriginal families can take those trailers at no cost—they have everything they need to be able to camp—and families camp around the riversides. It is culturally appropriate for them, it provides the sort of break they want, and it enables the person with a disability to go with the rest of their family and have an appropriate experience.

It has been quite a challenge for us to make our services individualised enough and culturally appropriate enough to ensure that Aboriginal communities have the best benefit, and it is a process that we are still working through. We have been running some flexible accommodation packages in the northern region, to support Aboriginal people to remain within their communities. It does not look like any other accommodation service, and it is completely individualised to meet their needs. That is the direction we are trying to head in.

CHAIR: Can you explain why it is hard to listen to them and be flexible? I do not understand that.

Ms McALPINE: We have a history of program boundaries, which can be quite rigid—for example, the debate on insurance on the trailer and public liability risk. It has taken us some time to work through those issues. But if we are really going to be responsive to Aboriginal communities this is exactly the sort of thing we have to do.

CHAIR: Is it unfair to say that it has taken us a long time to listen and be flexible?

Ms McALPINE: I think if you were living in an Aboriginal community you would have a fair degree of frustration with all governments in that you have articulated your needs a number of times and things have not happened to increase flexibility. I would hope that we are starting to see the change in that.

Mr MOORE: The program boundary is certainly a significant issue: it is the device that has stopped listening turning into action. Ethel has covered that. Partly related to this, and also going back to your issue about skilling, for us part of the problem is not the listening but the actual hearing of what is being said and then translated.

CHAIR: That is a very good point.

Mr MOORE: And to some extent we, as an organisation, need to have a much greater prevalence of Aboriginal staff within our operation. For the past two years we have been running a program of recruiting Aboriginal people to positions which are training level positions and then setting them up to see if they can compete for mainstream jobs at the end. We are committed to bringing in around 90 staff a year into that program within our group home network. We are also doing a similar thing within Aboriginal Home Care.

It is basically trying to build our capabilities as an organisation to be able to hear what is being said, and translate that into action, and also it makes a very significant difference in the lives of those Aboriginal workers, their families and communities that we are able to use our capability as an employer to deliver real jobs that bring in real wages as well. It is more than just simply a strategy to be able to become more responsive to Aboriginal communities. It is not a trivial part.

The Hon. TREVOR KHAN: Do you know the number of Aboriginal workers within your department?

Mr MOORE: Yes, about 5½ per cent of our workforce. I will provide that to you on notice. It is about 500.

The Hon. TREVOR KHAN: Can you break that down by region?

Mr MOORE: Yes.

CHAIR: Thank you for your assistance to the Committee. Please provide answers to any questions taken on notice, or answers to further questions sent to you by the secretariat. The Committee may ask you to return in September.

Mr MOORE: We are more than happy to do so.

(The witnesses withdrew)

RONALD CLIVE McCALLUM, Chair, Disability Council of New South Wales, Level 19, 323 Castlereagh Street, Sydney, sworn and examined:

AMELIA STARR, Senior Policy Officer, Disability Council of New South Wales, Level 19, 323 Castlereagh Street, Sydney, and

DOUGLAS HERD, Executive Officer, Disability Council of New South Wales, Level 19, 323 Castlereagh Street, Sydney, affirmed and examined:

CHAIR: It is an honour and a pleasure to have you people before the Committee this morning. Please state the capacity in which you appear before the Committee.

Ms STARR: I am here to support Professor McCallum and Dougie Herd in this inquiry.

Professor McCALLUM: I am here in my capacity as Interim Chair of the Disability Council of New South Wales, assisted by my colleagues, Executive Officer Mr Dougie Herd and officer Ms Amelia Starr.

Mr HERD: I am a public servant and I am here to answer your questions.

CHAIR: Would you like to make an opening statement before questions commence?

Professor McCALLUM: Yes, if I may, Chair. My name is Ronald Clive McCallum. I reside in Artarmon, New South Wales, and am currently Professor of Labour Law at the University of Sydney. From July 2002 until September 2007 I served my five-year term as Dean of the University of Sydney Law School. Currently I am the Chair of the United Nations Committee on the Rights of Persons with Disabilities, whose primary function it is to monitor the implementation of the United Nations Convention on the Rights of Persons with Disabilities. I am proud to say that Australia was one of the early nations to ratify the convention, in mid-2008.

Minister Primrose asked me if I would become the interim chair of the Disability Council of New South Wales and Her Excellency Professor Marie Bashir signed the relevant papers. I am interim chair until 31 October this year. No doubt the Committee has had Mr Andrew Buchanan appear before it in prior hearings. He was a magnificent chair of this council for the past eight years, but his term ended at the end of June and I am interim chair while discussions take place on advertising for new persons in the council and bringing in a new chair.

I assure you, Chair and members, that I shall do my very best in the next couple of months to work very hard and to help Mr Jim Moore organise the advertising and replacement persons for the council. However, my knowledge of various ADHC programs is a little thin, as I have been in the job for only a month and am wearing a few other hats. So my colleagues will fill in the blanks, of which there will be many. Let me briefly say that I think now is a very good timed to hold this inquiry. I commend the upper House Standing Committee on Social Issues for so doing.

As I said, Australia was one of the early nations to sign the disability convention. We now have 87 countries throughout the world who are signatories and, as has been said by the Chair and others this morning, it does make it very clear that persons with disabilities have rights as distinct from the old medical or social welfare model. It is one thing for a convention to say that we have rights; it is another thing for governments to implement those rights. Australia has been—and I am sure will continue to be—a very good international citizen. We do not ratify treaties willy-nilly; we do so after relevant discussions with the States in accordance with Commonwealth protocols to ensure that our laws can meet these obligations and, indeed, to work out how our laws can be reformed and altered to do so.

We persons with disabilities are generally treated well in this country compared with in many other countries around the world. We are the twentieth largest economy in the world, albeit that we have a very small population. This is not to say that we cannot do much better. As a person with a disability myself, I commend the Stronger Together program from 2006 to current. I note that the Minister who brought that program into being, the Hon. John Della Bosca, is now moving to help persons with disabilities organisations work on an insurance scheme to assist particular persons with profound disabilities. I am hoping that Stronger Together mark two, of which this council has been involved in the various consultative hearings, will continue that process.

We need more money in the disability sector. This morning the Committee heard from Mr Moore how the sector is growing, how funding is growing faster than the all-consuming health budget. Yet we know that our sisters and brothers with non-English speaking backgrounds still require more services and are underrepresented. Similarly, although splendid work is being done with indigenous Australians in New South Wales, we know that there is a long way to go. We are delighted to have a Committee of this House of this Parliament that is interested in this process. I have been pleased and warmed to be here this morning to listen to the cogent questioning. It is important that we persons with disabilities know that there are politicians who care about our plight.

I have lived a very fortunate and extraordinarily privileged life, largely because of family care and because of huge advances in technology which have lessened my sensory deprivation of blindness which, ever since we lived in caves for millennia, has been a tragic condition leaving most of my ancestors to beg and not have proper livings. I want to see all my sisters and brothers with disabilities live full lives through technology, through care and concern, through raising their rights via conventions and laws, and through governments that understand. Particularly, as a parent myself, I have deep concerns for parents with profoundly disabled children, who know that those children will most likely need care when it comes time for those parents to pass on. I think I have said enough. My colleagues may wish to say something.

Mr HERD: I suggest that we move to questions.

CHAIR: Thank you very much, Professor McCallum. We will now go to questions.

The Hon. HELEN WESTWOOD: My name is Helen Westwood. I would be happy for any of our witnesses to answer this question. Professor McCallum, you spoke earlier about the Stronger Together program. It was one of the questions I was hoping to ask our previous witnesses but there were so many areas to cover we ran out of time. Stronger Together is coming towards the end of its first five-year phase and currently consultation is taking place with the disability sector—and by the "sector" I mean providers, consumers and people with disabilities—about the future of the program. I would like to hear from any of you your view about the program to date and whether it has met the sector's expectations and what you think we need to be aware of in terms of the next phase of the program.

Mr HERD: I will go first, if I may, and then Ms Starr may add. The Disability Council of New South Wales was fortunate enough to be involved in what we would now call the Stronger Together consultations that John Della Bosca initiated. Our chair at the time chaired all of the consultations around the State. I think there were 11 in 2005 and I attended 10 of them. It is true to say, without wishing to be seen to be using hyperbole, that the atmosphere before the Stronger Together policy was put in place in the sector, as it likes to describe itself—the relationship between people with disability and the department, between people with disability and government, between non-government advocacy organisations and government and sometimes with non-government service providers—was hostile and difficult at times. My personal opinion is that that was because gross levels of unmet need meant that people with disability were not getting access to services and that family members were doing enormously difficult jobs under huge stresses to look after and care for both themselves and family members who ought to have been receiving services.

I wish I had been smart enough at the time to think about it. You sit there with John Della Bosca and you have to be awake, otherwise you are in trouble. He kept saying, "Money is not the only answer. Even if I had $1 billion I am sure we would not solve all the problems." I should have picked up on that quite quickly. The $1.4 billion that we subsequently got—which I understand was hard fought within the Cabinet at the time, although I obviously was not present—has made a very significant difference. There is no doubt about that at all. Amelia can say something about the more recent conversations through the Stronger Together II consultations. I have been to 2 of the 13. The character of those discussions was quite different. In the first round of discussions four, five, six years ago the anger and distress in the room was palpable. You could almost touch it. As you know, and I have said this before, I was not born in Woop Woop. You could see big, strong, wouldn't say boo to a goose Aussie guys sitting in the room on the verge of tears just knowing that they should not cry because that is not what big Aussie guys do but unable to hold back their anger and their frustration because of the inadequacy of the services that they had encountered at that time with regard to their son or daughter. That kind of experience occurred throughout the State.

Things have undoubtedly improved. There is no doubt about that at all. But I can put the caveat—I think you heard Jim Moore put it and I am absolutely sure you will hear from non-government representatives both in the service provision sector and in the advocacy sector—that as much things have improved and as good as things are now in comparison to how they have been in the past, we still have an awful long way to go. Your earlier conversations about the unmet need are critical conversations in this inquiry. I am sure you will hear time and time again from witnesses giving verbal evidence that they believe that their lives are constrained and limited by a lack of access to services, that there are large areas of unmet need and that although things are better they are simply not as good as they should be. I will let Amelia say something about the current situation.

Ms STARR: I would concur with Mr Herd's comments. I sat in on most of the consultations that were recently held. It is still very alarming and very hard to hear parents saying, "I have an extraordinary son or daughter with a disability. I know I am a good parent but I am extraordinarily exhausted with the system." Whether it is getting into the system, whether it is servicing the system, whether it is getting the right services, whether it is about being able to navigate linking to another system, there still seems to be a level of overlay that parents and people caring for people with disabilities find just too hard to get through. The comments about the complaint handling did come up in the consultations—"Where do we go with … We are not happy with the service?" That was certainly amplified in the discussions we had in regional areas where it is sometimes, "We have got nowhere else to go but the service we are using."

There are still a lot of issues obviously with the system. The issue around people from non-English speaking background being significantly underrepresented in the disability sector remains an issue. Even though there have been improvements, we are still seeing carers reaching that crisis point at various points when they are using the service sector. There is still a long way to go. Again, money is not the only answer but it is about making sure that when we are talking about client-centred or person-centred delivery we include the families in that discussion. We also need to realise that we need a whole range of supports that maybe are not currently there. I would say there are still steps to be made to move forward.

The Hon. GREG DONNELLY: My name is Greg Donnelly and I am a Government member of the Committee. I think all of you were here during this morning's evidence about the non-government disability organisations—now in excess of 460—that provide specialist services for people with disability. Would you care to comment about this issue of the growth of the non-government sector in this area and your general views in terms of the pros and cons of that development? Perhaps you could choose amongst yourselves who answers that question.

Professor McCALLUM: I will begin with a high-level statement. I declare here that I sit on the board of Vision Australia as deputy chair. I think what is needed in this country is more merging of non-government organisations. It has been happening but I think the large number means to me there is a lot of fragmentation of organisations doing similar things. I would like to see a Federal Minister for the non-government organisation sector because I think it is important that as many organisations in the same area should be merged as is practical and possible so that they can speak with one voice to governments, Federal or State. I think we have far too much proliferation. That said, I welcome very strongly the work of the non-government organisation sector. Without it we persons with disability would be in trouble. I now will let my colleagues give you the real answer. That is the high-level hyperbole.

The Hon. GREG DONNELLY: That is the strategic answer.

CHAIR: With a great element of truth.

Mr HERD: One thing I should have said at the outset and I should make it clear for the purpose of transparency and the record that both Ms Starr and I are employees of Ageing, Disability and Home Care, although we are employed to support the council being independent and autonomous. It needs to be on the record that we are employed by the agency that you are looking at. I also should go a bit further than that and say that I have worked for the council now for almost six years with four Ministers and two or three Directors General, depending on how you count it. Not once, not ever, has anyone tapped me on the shoulder and said, "A word to the wise, Dougie". It has never happened and I do not think it is going to happen. To answer your question, not wishing to contradict the professor of industrial law—I really do not want to do that—it was Mao who said, "Let a thousand flowers bloom", wasn't it? The strategy in the big picture sense is the right one. To have moved over the last five years to increasingly fund non-government organisations to deliver services to people is absolutely the right one so long as there is clear control and clear monitoring which should be independent and across-the-board, of course. You will hear more about that from National Disability Services later in the day. I think that non-government organisations are better equipped to understand the community in its complexity on the ground and deliver services than the larger government departments—which, of course, is not to criticise large government departments per se. What size should that sector be? I do not know. Is 460 about right? Should it be twice that number?

Dr JOHN KAYE: That is 460 separate organisations?

Mr HERD: I believe it is 460 separate organisations, I am not quite sure.

CHAIR: Yes, it is.

Mr HERD: I do know, because I did a piece of work on this last year at the request of the department, funnily enough, that in the United Kingdom where the UK Charity Commission regulates all non-government organisation charities in England and Wales there has been a very clear trend towards the merger of organisations. They have set up quite a sophisticated mergers unit working with the Charity Commission to advise non-government organisations on asking themselves whether or not by being an independent, stand-alone organisation they are fulfilling their objectives to the best of their capabilities or, given the way in which the non-government organisations arrive on the scene and develop, their enthusiasm and then perhaps in some circumstances not being able to sustain it forever whether or not it is a good time to look at a merger and coming together. I think it is reasonable also to note, however, that this is one of the more controversial areas in the non-government sector. I do recall going to one of the Stronger Together consultations—I think it was in Sutherland or Gymea—in which the Minister at the time asked the question about what size the non-government sector should be.

The Hon. TREVOR KHAN: Was the Minister at the time John Della Bosca?

Mr HERD: John Della Bosca. What size should the non-government sector be? How big? How small? How much do we fund it? A chief executive officer, who shall remain nameless, of a very large non-government organisation said, perhaps more honestly than he might have thought had he not just been answering the question, that he thought it would be only a matter of time before there was a much smaller number of much larger non-government organisations providing services across the State because they can provide consistency, they have economies of scale and all those things. Around the table about this size there were a small number of small, highly focused, very localised organisations with a good tradition, and you could almost see them running across the table to disagree with that view coming from a large non-government provider.

That tension is there and I think we as a council probably respect that tension and believe it might be healthy. Small locally based, fast moving organisations can respond to new developments and new needs in new areas if they have the infrastructure behind them. Large organisations can do a good job and benefit from economies of scale. It is not my place to say this but I think to be fair to the Government and the department they have recognised the complexity of it by moving into the realm of the industry development fund. I should not say any more because National Disability Services has ownership and carries that project forward, but it is an initiative that will look at how our non-government organisation sector should restructure and be governed and what is the role of people with disability in helping to manage and govern that sector to make sure that whatever size it needs to be it is the right fit. That is the question: What is the right fit rather than what particular size and number works.

The Hon. GREG DONNELLY: Ms Starr, do you have any comment on that?

Ms STARR: I think the question has been answered very well. From some of the recent consultations the evidence suggests that in a lot of regional areas smaller non-government organisations are able to do flexible delivery and they are a lot more responsive to particular clients' individual needs, and there was strong evidence to suggest that that was a great thing for those sectors. I agree that there is a unique tension between the number of non-government service providers and also the types of services they can provide. Certainly there is some merit in merging services where there are going to be savings in the administration of those businesses. That was also raised at the consultations. There might be six services in an area providing pretty much the same thing but they all have their own administration that they are supporting and people felt that money could be better directed to actual client delivery if those services were under a different kind of structure.

The Hon. GREG DONNELLY: My next question is not a Dorothy Dix question although it might appear to be so. It is to do with the issue of support for carers. I invite you all to comment on the issue of the support we provide for carers, but perhaps more importantly look into the future and give us your thoughts about how we could do better in providing support for carers.

Mr HERD: It is a complex question and it is certainly not for us a Dorothy Dixer by any stretch of the imagination. The system could not work without the informal network of support. It is that straightforward. The lives of many people with disability, not all, are made tolerable and possible because of the support they get from family members, friends, neighbours and others. It is usually women, usually mothers or wives or sisters, who put in hours that would probably be illegal if they were being paid for them and under terms that probably would not meet the occupational health and safety requirements that non-government staff are required to meet when they go into somebody's house. But because your wife gets you out of bed and helps you evacuate your bowels at six o'clock in the morning and was probably up at midnight washing the sheets that you soiled the night before you can let that happen. There is absolutely no dispute that without the immense contribution of the informal network of care we would be in much more serious difficulty in meeting the legal rights to citizenship that people with disability have, never mind just running a system.

How we support people in those circumstances to get out of that position is a much more fraught and sometimes contested question. There are conflicts of interest that need to be addressed openly in a constructive and positive dialogue. The interests of people with disability and the interests of carers are not always identical although they are broadly the same. I may have given this example to the Committee last time we discussed this matter but I will give it again. Someone can check the *Hansard* record to see if I am repeating myself. When I first injured myself 26 years ago the immediate response of the service system was to ask my mother if she would take me back into the family home that I had not lived in for 12 years and if she would provide support to get me out of bed in the morning. My mother's immediate reaction was, "Yes, of course", to which my immediate reaction was, "Not in a million years, mother", not because I did not want to live with my mother, although I did not, and not because I do not love her, but because it would destroy the family relationship. It would get in the way of us being mother and son because my mother would have been trapped into being the person who got me out of bed for the next 25 years of her life until some crisis arrived and a formal service came in and picked up the pieces. That is not fantasy on my part, because I know it happens to people.

We need to build a system of supporting people to have natural family relationships, which means I live with my partner and she assists me with some things and I assist her with other things. People with disability contribute to family life as well as receive from family caregivers. We need to not create familial caring as a ghetto. We need to try to make sure that people with a disability can live autonomous, independent lives so that family members can live independent, autonomous lives.

That brings me to the Productivity Commission inquiry into disability care and support. This is something about which there probably is not going to be unanimity from the people who will give evidence to you over the next month. I think our council, so far as we are able to understand what is being proposed, is unambiguously clear that we need to move further along the road of making a fundamental, irreversible paradigm shift in the way in which we organise these support services, which means that we need to resource people, give them the wherewithal to begin to take more control over the services they receive and then work out ways in which they can organise their lives so that not everybody who comes into their life is paid to come into their life, but some people are. That might mean that we work out ways in which we can liberate our mothers, fathers, brothers and sisters from the job of caring. Most of the time most of them will want to do it because most mothers, father, brothers and sisters love the people they are caring for. It is not always true and there is abuse and there are difficulties, and relationships get destroyed, but we need to resource people to return to them the normally family relationships. I do not think that means paying carers, but sometimes it might. It means creating a new way of delivering services that give individuals real choices about what they do with their day, when they get out of bed, when they go to bed, who they see during the day and how they get to and from wherever it is they go to.

As usual I am taking too long, but it is a complex question. One of the things that I think is a problem arose in the last conversation I had with the chief executive officer about respite. I think respite should be an outcome, not a place you go to. We have created day-centre-based respite facilities only because we have created a tension between people with disability and those that care for them. You do not need centre-based respite if you have provided a network of support around people. Here is where the tension comes in that I think we will have to look at in future. If it is true that the United Nations Convention on the Rights of Persons with Disabilities says that people with disability have rights as citizens, then removing them from their home to give someone else a break is a breach of the convention. We will have to look at that tension in reality in the future, but I know what the reality is. We are not going to close down any of these facility-based respite centres tomorrow. That would be absurd. Nobody is going to suggest it, but the sooner we begin to address those tensions the better. So anyone who thinks questions about carers are Dorothy Dixers is not part of the industry.

The Hon. GREG DONNELLY: Would either of the other witnesses like to elaborate or make additional comments?

Ms STARR: I think Mr Herd has covered it well.

Dr JOHN KAYE: Can I seek clarification? Professor McCallum, is it your opinion that respite care, as Mr Herd said, is outside what is permissible under the international convention? Is that what you were saying?

Mr HERD: No. I was saying the traditional way of doing respite is that to give the family member a rest you take the person with disability out of the home. In removing an individual from his or her home the question of consent can be debatable. It comes into tension with the notion that you are a citizen with rights. If that is your home and that is where you live and you need some support, stick it in there.

Dr JOHN KAYE: Are you saying that in order to conform with the right of a citizen to stay in their own home respite care should be redesigned so it is delivered in the person's home?

Mr HERD: The touchy-feely slogan is that respite should be an outcome, not a place. If you build the network of support the need for the traditional kind of respite response that we have built into the system and which people quite understandably say we need more of begins to vanish. To go back to the original discussion, it was put quite well in this building at the time by then the Minister, John Della Bosca, and the then director general of the department, Brendan O'Reilly, who has another role in government now. Part of the tension that exists is that disability service provision is a bit like a cliff. Traditionally we have organised our safety net by having an ambulance at the bottom of the cliff. What we should do is put a fence at the top. You cannot save the world; people just keep falling off the cliff because we are building the fence at the moment. You have to pull off the trick of having both at the same time, but both cost money and the transition costs money. You would probably have a stronger view than I have about the extent to which the taxpaying public will bear a doubling of the disability budget every five years. Because when we talk about Stronger Together II, I have yet to meet a human being on the planet who is prepared to say in public that they think Stronger Together II should be funded for anything less than $2 billion worth of new money. That takes it up to $5 billion in five years' time. In 10 years' time it is doubled again.

Dr JOHN KAYE: Are they annual figures?

Mr HERD: No, it is every five years. Currently expenditure of Stronger Together is about $2.2 billion a year, yes, you are right. Everybody says with new money at today's figure it needs another $2 billion. That is just not sustainable unless, as politicians going to the taxpayers for votes next March you think it is, in which case I think you will hear from every single person who gives evidence, "You go for it".

CHAIR: We will give a tax cut as well.

Mr HERD: It is a very difficult circle in the square. I am only saying things I think are in the public domain. Premier Keneally has indicated that her Government will give a statement on perhaps the number by the end of the year but it gives you an indication, I think, of how you people feel. We are all waiting with bated breath for that number because people have been looking at the Stronger Together II number in the industry, in the sector, the community almost since the day after Stronger Together I was fully funded and that is because it is a very clear indication of the extent to which the big elephant in the room that nobody could describe properly, unmet need, affects the lives of people with disability and their families every single day, because unmet need is just big.

Professor McCALLUM: The convention does not prescribe what behaviour people should engage in. It gives persons with disabilities the same human rights as others. This Committee held an inquiry into substituted decision-making which is at the heart of Article 12. What the convention prohibits is that if adult citizens without their consent are forced into situations—are falsely imprisoned, institutionalised without proper judicial oversight et cetera or pushed out of their homes—we have to grapple with the changes in giving people these human rights and we have to do it within the confines and operations of government.

In relation to the costs of disability care—and it is true that they have gone up faster than the Health budget—nothing ever goes up exponentially forever, whether it be health, disability or defence. At some point as a society we have to start rationalising our priorities and this is a difficult issue for government. One of my concerns about the so-called insurance scheme is that the word "insurance" lets people think that this can come out from an insurance levy and it will not affect the tax base. I know that, for example, when Medicare began it was supposed to all come out of the Medicare levy and that the rest of tax would be free from health costs. That never happened and it will not happen in the disability area.

I welcome the Productivity Commission and the National Disability Strategy of the Federal Government that Premier Keneally has accepted but I think we are five years away from sorting out through an insurance scheme how we are going to fund these processes. I think it is going to be a brave government that will increase the Medicare levy or a type of Medicare levy on tax. But I do not think governments can or should evade their responsibilities by saying tax cuts are more important. These are fraught questions. They are questions for the community and as our mediators they are questions for you the politicians to help us solve.

The Hon. TREVOR KHAN: I refer to an issue that was put to the previous witnesses that related to the delay in assessments for community support team services. I refer to page 54 of the department's submission. In that regard I am particularly interested, seeing we talk about bottom of the cliff and fences at the top of the cliff, the 0 to 5 group, whether the council has a view with regards to the delay in assessments of children, infants, being undertaken and whether that is an issue that is taken up with you by people you represent. If so, do you have some suggested solutions to the delay that appears from the statistics?

Mr HERD: We have a view and it is partly informed, because I think five of the current council are themselves parents of children with disability, one of whom happens to be Sylvana Manhic, who is chief executive of the Pathways Early Intervention Service in Marrickville. For us early intervention is simply one of the absolutely essential powers of a successful disability services system. Whether that is in the 0 to 5 or intervening area after an accident, it is critically important we would think, based on what Sylvana tells us both from her professional experience and as a mother of a child with profound disability, the intervening area is absolutely critical.

I think at one of our council meetings four or five months ago we were having discussion around this very topic, particularly based on the experience of parents who were saying that at the point of diagnosis they were given the news that they had a child with a profound disability, given some information and in their experience, and in the experience of other family members that they had contact with, they had no clear pathway about what happens next. They are processing all kinds of things. The happy news of the arrival of their son or daughter is not as happy as they thought it was going to be. They are grieving but they are getting to know their son or daughter and they are still full of that enthusiasm but they are being told about disability services—they are either being told about it and they are not quite sure how to get there or they are not being told about it and have to find a way to self-help groups and others.

And that is before you even get to assessment. Those delays are already taking place, so our view in a policy sense is absolutely clear but it is a mother and apple pie statement that the earlier an assessment gets done the earlier the intervention can begin, the better the outcomes for people with disability in the long run. I am not an operational person so I do not know what happens and how things work but from what I observe these kinds of questions have been looked at and attempts have been made to address them in another area of the Government's work, which is the procurement of appliances for disabled people under NSW Health. We are particularly concerned in relation to the provision of equipment to children which is causing extensive costly problems for the public purse because you would have delays in the assessment and provision of equipment that could take up to a year or 18 months. In the life of a five-year-old that is an eternity and we have to reassess, re-provision. That is what goes directly to the question about ADHC funded services and the truth there. I believe it was something that is referred to frequently at the Stronger Together II consultations. I will pass on to my colleague who went to more of them than I did.

Ms STARR: To try to pick up on some of the points in your question, certainly under Stronger Together I more funding was made in terms of the extended services funding for early intervention services. From consultations, that was received incredibly positively in the regions that did receive that additional funding. They were actually able to pick up on some of those waiting list issues in terms of enhancing capacity and also extending their catchments. A service in Lismore was able to go 200 kilometres further in each direction to try to pick up indigenous children and people that were in more rural and remote areas who would typically not fall into any kind of service until that child ended up at school. But the fact is that was a particular program of funding. What the service providers were saying is that that level of funding is needed: it is not an extension of services, it is actually this is the level of funding that is needed for early intervention services.

I would have to say too that early intervention 0 to 5 is a much more well understood area of disability generally because there has been much more funding pumped into it over the past five years. Picking up on Mr Herd's point, we do not really think of early intervention throughout the lifespan. Disability happens at all different times in people's lives and I do not think we have the same level of response to people that may have acquired disability later that we do when we are trying to deal with early intervention at the earlier sense. I think there is a bit of a misnomer there where we say, "If we put all the money in before five they won't need anything later". If anything, they will need more later because we are actually building capacity in those little minds to be able to go out and do work and get jobs and go to university and all those kinds of things if they are capable of doing those things. We are actually doing the right thing by saying, "We want to make sure that we give those children the best chance at living a productive life" but we need to make sure that we are investing that level of intervention through people's lives.

The Hon. TREVOR KHAN: What I am looking at is on the basis of material on page 54. It is the largest group, the 0 to 5, where there is delay. If more funding is being pumped into that area than any other to ensure that there is not delay then on the basis of the figures it would seem that it is failing. In part I am interested in your view on whether it is simply a question of the adequacy of the funding, or is it an issue of process that is resulting in delay in the assessments taking place? Is there a bureaucratic malaise that is frustrating quick assessments being undertaken?

Professor McCALLUM: I do not think we can answer that.

Ms STARR: It seems that the answer fits somewhere in the middle, to be honest.

Professor McCALLUM: I think it would be fair to say that you really need some evidence from people like our council member Sylvana or from organisations involved in this. I do not think we would want to ascribe bureaucratic malaise necessarily without having evidence ourselves. We believe it is a critical area. Like Mr Herd, I believe all areas are critical particularly after accidents but I do not think we are in the position that we can give you meaningful evidence on that.

The Hon. MARIE FICARRA: Why are there unidentified unmet needs of persons with disability from non-English speaking backgrounds? Is it cultural because often a lot of those families believe it is their responsibility to manage on their own and look after their own or is there a multitude of problems with lack of information and confidence to utilise the system? Where do you think we are going wrong? What should we be doing? I know this is a big question.

Mr HERD: Some aspects of all of those things. What is clear, and I am sure the Multicultural Disability Advocacy Association will say something about this if it is not already in the submission, is that you are probably going to see what John Della Bosca said. I am going back to John Della Bosca. We engaged the council four or five years ago in an exercise in partnership with the Multicultural Disability Advocacy Association around access to services for people from a non-English-speaking background and those with cultural and linguistic diversity—we prefer the first term, to be honest—and Minister Della Bosca acknowledged and said that he believed that there was an institutional racism in the system. I know that is a slightly controversial notion for some people to accept. That is not a criticism of individuals; it is not saying that workers are racist, but there is a set of cultural assumptions that make it easier for me as a white middle-class man to get access to services than if I came from any other background. There is no doubt about that at all.

Lack of access to information, services organised in a way that make it easier for me to get into them and access them and understand what is going on. Language differences are important. A number of people tell us—it is true also in the Aboriginal communities—that in some communities, some languages, there is no word for disability. So if you organise a disability services system you may not even know that there are support systems around for you to get access to. There may be cultural values in accessing the kinds of services that we organise but the responsibility is on the system to develop cultural competency, to develop culturally appropriate services. I am a white Anglo-Saxon person but I am talking about cultural diversity. How more inappropriate can you get! But easy stuff, making sure that if you are going to run a community transport organisation that you think about gender—you think about cultural diversity when it comes to how you use the bus.

We were recently at an Aboriginal community transport conference in Coffs Harbour where the points were made that if you have got a set of rules about community transport that say you will only take the client you will not take members of the client's family. If you happen to be a client with a disability, a grandmother, who is also part of an extended family, either because you come from India or from Coffs Harbour, if part of your extended family role is to look after your daughter's four-year-old kid but the community transport organisation will not allow you as the client to take the four-year-old kid with you, you need to rethink how you organise community transport.

We think it is all the things you talked about. I think it is reasonable to observe that the department does have a cultural competency strategy, which it is attempting to put into practice. I believe it has been more successful now than it used to be in the past, but the numbers are pretty clear: 25 per cent of the population of people with a disability come from a non-English-speaking background; fewer than 10 per cent of clients come from a non-English-speaking background. The maths is very simple. It is not the fault of the client; it is my fault. I am a white Anglo-Saxon public servant and if I do not change the system will not change.

CHAIR: We have run out of time. Thank you very much for being here with us this morning. We may get you some questions in the next 48 hours or so as we think through what we have been unable to ask.

(The witnesses withdrew)

(Luncheon adjournment)

EMILY CASKA, State Policy Coordinator, National Disability Services, Level 4, 60 Pitt Street, Sydney,

PATRICK MAHER, Chief Operating Officer and State Manager, National Disability Services, Level 4, 60 Pitt Street, Sydney, and

KATHERINE MORE, Manager Workforce Initiative, National Disability Services, Level 4, 60 Pitt Street, Sydney, sworn and examined,

GORDON DUFF, State Manager Policy and Projects, National Disability Services, Level 4, 60 Pitt Street, Sydney, affirmed and examined:

CHAIR: Would you care to make some opening remarks incorporating your functions and what your organisation is all about?

Mr MAHER: Certainly. I have a brief introductory statement I would like to read. It will cover a few areas. It is probably best if I go through that rather than digress too much. Firstly, I thank the Committee for the opportunity to provide input to this inquiry. The inquiry into services provided or funded by ADHC is timely with deliberations about the future of Stronger Together currently taking place as well as the equal remuneration case currently before Fair Work Australia being led by the Australia Services Union. Of course, this is seeking to significantly lift wages across the sector. In addition, there has been increasing recognition in recent years of the strength and abilities of people with disability in line with the growing acknowledgement of the critical role played by formal and informal services and supports in assisting people with disability to achieve their goals and live their lives commensurate with those of all other citizens.

I acknowledge the New South Wales Government's commitment to deliver better services for people with disability and their families, most notably through Stronger Together, which has tangibly reshaped the disability service system into one that is increasingly innovative, responsive, robust, efficient, integrated and sustainable. This is a journey that commenced nearly five years ago and continues to grow and change as we move forward facing diverse demands and changing economic and political climates. During this time the New South Wales Government has acknowledged openly the importance of partnership with the non-government sector, underpinned by a clear recognition of each party's critical role in providing quality services and life outcomes for people with disability in New South Wales. This partnership approach has been at the core of NDS's relationship with government and, in particular, with ADHC over the past six years. Prior to that time, as Dougie mentioned earlier today, we lived in a very adversarial environment, but it is good to sit here today and say that is no longer the case.

Anecdotal and quantitative evidence reveals a genuine shift from outputs to outcomes and improvement in the lives of people with disability in New South Wales through increased access to a robust and diverse service system founded on strong principles of choice and voice. For people with disability and their families to avail themselves of every opportunity to reach their potential a flexible, innovative and sustainable service system has to be accessible to all. Getting a service response right requires realistic investment that adequately reflects the actual cost of service delivery combined with capacity-building opportunities and a genuine integrated partnership between government and the NGO sector. In looking at the sector, that is, those organisations delivering services and supports, significant investment has been directed in recent years towards building the capacity and capability of the service system in New South Wales based on increasing its capacity to deliver specialist services as well as strengthening linkage with mainstream and universal services to build the capacity of the system as a whole to respond to the needs of people with disability, their families and carers.

Central to achieving this is the partnership approach between the Government and non-government sectors, a climate of classical aberration that has not yet been achieved by our colleagues in most other portfolios. This is something of which NDS is proud and will continue to cultivate moving forward. Whilst we feel it is important to reflect upon the successes of Stronger Together and other key initiatives to date, we also openly acknowledge that more remains to be done, particularly when we look at future growth of the New South Wales disability services sector, which is driven by unmet need and increase in demand. At the core lies a commitment of enhancing the economic and social participation of people with disability and their carers in line with their inherent human rights encapsulated most recently in the UN Convention on the Rights of Persons with Disabilities. Involving service providers as full partners in care is central to achieving this.

The transformation of the rhetoric of rights into the reality of participation and inclusion is the intended outcome of the following policy and funding proposals. The New South Wales Government is a key catalyst in close partnership with non-government organisations, people with disability and their families. I stress our firm belief that the issue of disability is not and should not be a political one; it is about people's lives and about how they live their lives as valued members of an inclusive and just New South Wales community. NDS believes strongly that continued commitment to the second five-year phase of Stronger Together is the central means by which the New South Wales Government will achieve a more streamlined, more efficient, more appropriate and more innovative service system. An injection of additional funds by the New South Wales Treasury is undoubtedly needed to meet unmet need and growing demand for disability services into the future. In addition, the power of continued commitment to a genuine partnership approach between government and the NGO sector cannot be underestimated and is critical to achieving quality outcomes for people with disability, their families and carers in New South Wales.

As the scale and scope of the disability services system has grown and become more diverse, so too has NDS as the peak body. The range of our work across policy and projects has meant that we work in collaboration with DADHC while also maintaining our independence when advocating for change or systemic improvements. At the end of the day, we are all working towards the same goals, that is, to create a better system and better community for people with disability and their families and carers. To this end, a non-adversarial partnership approach has proven incredibly effective in achieving the significant milestones to date. Given the size and scope of the sector within which we currently operate, I bring with me today three representatives of the NDS executive team who each possess expertise relevant to this inquiry and who will be able to provide you with greater insight than I possibly could do on my own. For the past 15 years I have worked directly in the disability sector, the first eight years as a deputy chief executive of a fairly large regional service provider and the past seven years as the State Manager and COO of NDS, the peak body. Prior to that I had 15 years as a voluntary board member having gone to a country town and been roped in pretty quickly when I arrived to work on the board of a service.

Gordon Duff, our State Policy and Projects Manager, has significant experience overseas and is a great asset to NDS and to the sector because of his exposure to and experience with policy development in the area of self-management rules and individualised funding. Emily Caska is our Policy Coordinator. She is the one who draws all of the loose strands together and keeps us informed as to how all the different initiatives that are happening across the sector blend together and keep us all relevant. Kate More, who has been with us for about two years, also has worked in the sector overseas and joins us in our organisation to run the very successful carecareers campaign, about which, no doubt, she will have an opportunity to speak.

In concluding, I want to take the opportunity to acknowledge our current Minister, Peter Primrose, and his four predecessors, as well as the Chief Executive of ADHC and his predecessor. They have all been great, and I value the fact that we have more people around the Cabinet table who understand our issues. I also take this opportunity to acknowledge Jim Moore and his team for explicitly recognising the unique and valuable role played by non-government organisations in building social capital, leveraging community connections and supporting people with disability to get a life, get a better life, and to live life on their own terms.

I do not want to let the opportunity go without also noting our ongoing engagement with the shadow Minister Andrew Constance, and acknowledging his non-adversarial approach and true commitment to the disability sector in New South Wales and his valued interactions with members of all political parties, most recently with Ian Cohen and the Greens, which is seen as critical in this important portfolio and has become one that is truly non-adversarial.

We believe that the constraints faced by ADHC are similar to that of any agency seeking to provide or fund services and supports within a context where demand outweighs supply. As with all large government departments, much effort, energy and ingenuity is required to manage demand without the inflow of adequate resources to do so. National Disability Services strongly believes that, looking to the future, the story of people with disability should not be one for all services and supports alone. Instead, we are moving towards a more sophisticated system where people with disability are firmly at the centre, choice is paramount, and reliance on formal specialist disability services is reduced. It is important to say that the community has a key role to play in this new world, as do other portfolios such as Education, Health, Housing, Community Services, Transport and others. Disability can affect anyone and therefore requires a response by everyone.

In conclusion, a national disability insurance scheme is the next logical step in ensuring a long-term, workable disability services system free from the constraints of electoral cycles and the current struggle for funding. As many of you are no doubt aware, the Productivity Commission is undertaking a public inquiry into the concept of a long-term care and support scheme, examining its design and costs. The national disability insurance scheme concept is absolutely paramount. We are in a strong bid for additional funding Stronger Together II, and I am happy to also go on record as saying that needs to be well in excess of $2 billion for the second five years, to maintain the identified growth that is needed—

Dr JOHN KAYE: Could you clarify whether it is a $2 billion increase in the annual budget?

Mr MAHER: It is $2 billion over five years. I am saying $2.5 billion over five years additional funding to complement what was to be $1.3 billion over the first five years of Stronger Together. That is on top of the approximately $2.4 million a year that the portfolio carries. We cannot afford to be sitting here in five years time and talking about Stronger Together III; we have to have a properly resourced sector. Thank you for the opportunity to make that rather lengthy statement.

CHAIR: On pages 9 and 10 of your submission you refer to the vexed issue of unmet need and undermet need. On page 9 you discuss the difficulties in assessing unmet need and the adverse consequences, and the impact that the lack of accurate assessment tools has on the delivery of disability services. Firstly, could you elaborate on this and offer suggestions as to how Ageing, Disability and Home Care can address this area? Secondly, you talk about the issue of undermet need and the fact that National Disability Services has received anecdotal reports from service providers indicating that current services, supports and hours allocated to individuals are not adequately or appropriately meeting the needs. What actions would you suggest Ageing, Disability and Home Care should take to address the issue of undermet need?

Mr MAHER: I do not want to sound flippant in responding. The answers to both those questions are the same, and that is that we are dealing with an environment where you have a department that has a finite budget to meet a need that is far in excess of that which they can fund. So without significant additional funding being brought into the sector we are going to have unmet need. There is a capacity to identify some of that unmet need. I think undermet need is probably best explained in some of the active ageing type programs that Ageing, Disability and Home Care has out there where people may have been funded to receive one, two or three days support a week when in reality their needs are for four or five days or their family's or carer's needs are for four or five days. So there is a need being met but it is not the full need that would be sought if the funding was available to do it.

I would have to say that I believe that within the confines of what is available there are probably pretty good outcomes being achieved. But that is far from saying that the outcomes that we would all aspire to are being achieved. They are not—and they cannot be, with the funding that is available.

CHAIR: Are you able to make an educated guess as to the percentages of need?

Mr MAHER: Anecdotally, if we look at the growth in the budget for Ageing and Disability in New South Wales in the last five years and we project that out, my understanding is that the figure of something like 14 per cent of the State budget within five years would be required to just keep up with the trends that we are seeing occurring as we are in a position to offer more and more services because of Stronger Together. But I cannot put a number on what the need is; it is very broad anecdotally.

The Hon. TREVOR KHAN: You mentioned State budgets. What is the anticipated growth in expenditure that is shown in the forward estimates, if any?

Mr MAHER: I will have to take that on notice. With regard to the forward estimates, I believe this year we received about 9 per cent compared with the average across the State of about 6 per cent across all portfolios. As we say, we are still significantly below what is needed. But we are getting attention at the moment.

The Hon. TREVOR KHAN: Are there inequities between ADHC-operated and ADHC-funded services?

Mr MAHER: There are inequalities.

The Hon. TREVOR KHAN: That will do.

Mr MAHER: The obvious difference is that the wages that are paid to people working in ADHC-operated services are significantly higher than those for people who are working in ADHC-funded services. We generally work under the **Social and Community Services** Award, which is one of the awards that will be covered by this pay equity case that is being taken before Fair Work Australia. We are fully supporting that: we are united. I have to say everyone is united in that on the basis that when it comes in it is going to have to be funded. But in our sector, the average wage is, I understand, about 60 per cent of the national average wage for people working as carers in the disability sector in New South Wales. That is just too low, and we do struggle to attract people to the sector. However, we have had some significant successes in the past 12 months through the carecareers campaign, which did turn up a lot of information and gave us a lot of insights into what is happening. I would welcome, if you would like, Kate More to give you a five-minute briefing on the carecareers campaign, where it came from and what we have discovered.

Dr MORE: I guess it allows us an opportunity to get to know the workforce that we have and to understand why people are not joining our workforce, because we know that we need to grow our workforce to keep pace with the investment that is being made in the sector and to meet any future need that we are talking about. We found very quickly that the sector does not have the visibility, that it does not have the understanding of what work in the sector involves, and that there are career pathways and career opportunities within it, and multiple careers. So, we needed to develop an initiative to open up and shift perceptions that were blocking people joining the sector. Most fundamentally, that can be summarised as people believing that the work done here is not professional, it is done by volunteers, and that it used to be done by people who are saints and those who recognise their need to grow their bodies so they would not put themselves on the recruitment path.

So the biggest job before we even tried to create training opportunities and skilling a workforce that we attract into the sector is to get them to see it as desirable in the first place. That is fundamentally, in a nutshell, what carecareers has been about. But in terms of implementation, it has also allowed us an opportunity to understand the pressure points that organisations experience in terms of recruitment and attraction and retention, and to respond to those and provide some very skilled recruitment expertise directly into organisations that are moving to attract people. It is also allowing us to have direct relationships with respect to candidates. I can say that within the first six months of being implemented carecareers has attracted over 170,000 individuals to the sector. So there are people out there who do want to work within the sector. Pay is certainly not the only issue; there are many other benefits that the sector is able to offer.

The Hon. TREVOR KHAN: We deal with another inequity issue, the issue of waiting lists: the provision or quality of services across regions and the like. Are there inequalities or inconsistencies across regional areas of ADHC?

Mr MAHER: Gordon may like to answer that.

Mr DUFF: We often hear from some members that services often need other things to be occurring at the same time in order to get positive outcomes. The one they raise the most often is transport. Just simply being able to get to services or to be on the receiving end of allied health potential professionals or care workers you need other things to be in place like a robust transport infrastructure. That is the one most often cited by our members. All other things being equal, a provider in the north of Sydney would be funded to deliver a unit of care or some service in the same way as someone in Tamworth or regional Australia might do as well. It does not really take account of what is needed to get that service to the person.

The Hon. TREVOR KHAN: Can you explain that further? I do not know whether Tamworth is a good example, but is it that it is more expensive to deliver the service in that environment than it is in North Sydney? Is that what is being said?

Ms CASKA: Yes, it certainly can be. That is a bit of a shift in the way that ADHC has been funding the non-government organisations, taking account of their geographic location and the location of the people that they are trying to service. We are seeing more and more across service types that they are adding an additional funding component for rural and regional services. It is not across the board yet, but it is certainly rising. In our submission as well, in terms of looking across the regions, ADHC is structured across six regions across the State. There certainly is value in that, because they can respond regionally. We certainly support that structure.

However, there are some slight inconsistencies that we continue to work with ADHC on. The main ones are inconsistency and the application and interpretation of policies. The policies of our providers who work in different regions can be implemented completely differently, depending on which level of middle management is implementing the policy. Also, there are some concerns from NGOs around procurement processes. We have noted in our submission that ADHC Central was certainly aware of this. There are concerns by some of our member organisations around preferential procurement of services, particularly in the western regions and the northern region. There is some fear of small providers being taken over by large statewide providers, and that was very clear in our consultations with the sector.

Also, there are issues with portability, the regional structure of a big organisation operating across different regions. If, say, you are in metropolitan south and you have five vacancies in respite and in southern you have five people on the waiting list the ADHC regional structure does not allow you to manage your own internal capacity because you are cutting across their region. Sometimes that can be difficult. Another thing is continuity. There is quite a large turnover of ADHC regional staff, so our members find it a bit hard to build a relationship with those middle managers to understand their business.

The Hon. TREVOR KHAN: Where are regional offices located?

Ms CASKA: The six regions are western, northern, southern, met north, met south and Hunter. In the larger regions there are lots of regional offices. For example, in western there are regional offices in Tamworth, Orange, Wagga Wagga and Albury. They are all part of one monitoring region.

Mr MAHER: The regional directors are located in Queanbeyan, Lismore, Newcastle, Dubbo and two in Sydney, one at Hornsby and one at Burwood.

The Hon. TREVOR KHAN: Very regional. But it is the regional offices such as Tamworth and Dubbo where there is a turnover of staff. Is that where the problem lies?

Ms CASKA: It is not isolated particularly to the regions. I am talking of regions as in the ADHC breakup of regions, but I do not mean in terms of regional New South Wales with the turnover. It is across all regions in that middle management procurement type contract management level, which is where NGOs have most interface with ADHC.

The Hon. TREVOR KHAN: In your submission you distinguish between individualised approaches and individualised funding, citing individualised funding as one of the mechanisms to achieve greater choice and control for people with disabilities, their families and carers. Can you detail other mechanisms that achieve that outcome within the service system?

Mr MAHER: I would like to defer to both these guys, because they are the people who know.

The Hon. TREVOR KHAN: It is good that you share it around.

Mr DUFF: Appended to our submission is our current position on individualised funding and what it takes to work. This is an area in which there is a certain lack of clarity of language in describing personalised approaches in disability services. A lot of people describe individualised funding and they think they mean the same thing when someone else talks about it. We say that there needs to be a continuum of different offerings to people with a disability. One of those, right at the extreme end, is the direct payments model, which would require you to set up an ABN, where essentially you become the employer of that person, with the money straight into your bank accounts. That is the kind of attendant care model that we heard from the department this morning. That has had a very low take-up. In fact, it has had a very low take-up internationally when it has been offered.

Moving on from that, along the continuum, there is a range of possibilities that involve people being clear about their allocation—doing functional needs assessment, translating that functional needs assessment into a dollar value and then being very clear that that is their money, but not necessarily having to manage it, and now dealing with the administrative burden around that. There are other models, like virtual budgets, where the money can sit with a financial intermediary, or the department, or the service provider, and that person is supported to draw down that allocation to direct their own life and get a life.

That can move right along to a looser allocation for a place in a day centre or supported accommodation. There is a range of different models that we say can enable choice and voice and control, and they do not always need to be the passporting over of money to the service recipient.

The Hon. MARIE FICARRA: In your submission you raise the need for independent monitoring processes within the disability sector. Why do you feel that is needed?

Mr MAHER: One of the long-held concerns in the sector, which precedes the Department of Ageing, Disability and Home Care and goes back to the days of ADD and so on, is the concept of the funder being a competitor, in being the policeman. Just at the end of the day it will cause potential problems. At the moment there is nothing out there that is really sticking out as being a problem for us, but there is a recognition that as we move to a more outcomes-based model we should have an environment where there is an independent review of what you are doing, and that you are meeting your contractual obligations under your funding agreements.

At the same time we do not want to rush into it. We have had three years of something called the "integrated monitoring framework", which has sufficed as an interim measure, but it is nothing more than an interim measure. The model we are working towards is along the lines of a matrix, where we would hope that we will end up with something where we look at all your compliance obligations. If you are a nice, open client organisation how many boxes in the matrix do you tick? If you are a public company, or an incorporated association, how many boxes in the matrix do you tick? If you are a national disability service provider, say funded by the Federal Government, you must meet the Federal disability standards, so how many boxes in the matrix do you tick?

We may end up with a concept where there are 36 boxes, and only three are left to tick. Let us come up with a system that looks at those three. We do not want to be checking the checkers if they are independent. Hopefully the Industry Development Fund will address that issue as one of its key plans. As the CEO said this morning, we are looking forward to an outcomes base. We really look forward to the day when the board of an NGO can accept its responsibilities that it has contracted to deliver, certain outcomes. We need to get away from saying we gave them $100,000 to do the job, so show us where they spent every cent. That is an outdated model, provided that they are getting the outcomes that they believe they purchased.

Again, not meaning to be flippant, but the Government does not ask General Motors what it does with all of the money it gives them every time they buy a Holden motor car. So why are they asking us? If we are a good service that is recognised to be able to provide the services and we have an independent means by which we are giving certification that we are giving a quality service then allow that board to sign off with the same legal obligations that they sign when they sign their account annually, that they are meeting all those obligations. And then allow an independent assessment, as you do with your auditors in the financial environment, to come in on an ad hoc basis and verify whether that is happening.

Of course, you still have to have a complaints mechanism so people have the ability to come back and question that. It is a leap into a brave new world. It can happen only if there is a genuine partnership between the department, government, and the sector. I believe we are probably in one of the best places we have ever been to try to achieve that.

The Hon. MARIE FICARRA: Regarding complaints handling, in your submission you allude to improvement of certain aspects of DADHC's complaints handling. Can you elaborate on that?

Mr MAHER: Probably the stronger point we were wanting to make was that there is an environment for complaints handling but we do not have a strong environment for positive commentary in terms of the services people are getting and how the good practices can be shared through a feedback mechanism that might be the opposite of a complaints handling system. We would like to see a bit more strength built around that.

CHAIR: Does that revolve more around the user and the user being the one that highlights issues that need to be addressed?

Mr MAHER: Either way. Absolutely. The service users have to have their rights protected and a proper complaints handling mechanism, which everyone in a funded organisation should have in that regard. We would also like to see service users have the capacity to highlight where they believe they are getting a service that is really good. You might be able to learn from that and utilise that lesson in other areas.

The Hon. GREG DONNELLY: Thank you for coming along to give evidence today. Most of you were present this morning when evidence was given about the number of non-government specialist service providers and the number recorded was 460 or thereabouts. Could you comment on that in regard to your understanding about how that has grown over time, the absolute number itself, what projections you might have in terms of growth of those numbers over time, and any general comments about the size of that sector.

CHAIR: Before you answer that, your submission states that there were one million unmet needs, as opposed to 460,000.

The Hon. GREG DONNELLY: No, I am asking about 460 service providers.

CHAIR: Sorry.

Mr MAHER: Regarding that statistic, it depends on where you call the numbers from. We say it is a million, but it is what group of statistics we are using and whether we are defining severe and profound disability or people with a disability. I will pass this to Emily Caska—she knows the answer. I thought we might have been able to convert away from the other question because we are an issue-based organisation. Do I want to see a reduction in the number of service providers? Probably not. There are so many different approaches to the number of service providers. One of the astounding statistics that I heard, probably about three years ago, that made me question the structure of the sector was that overall ADHC funds just on 900, so it is not just disability; it is across all portfolios.

Forty-seven per cent of those services chew up 4 per cent of their budget. There is an incredible amount of duplication of unnecessary administration going on in some very small services across the sector. Nationally we have just on 700 members. More than half of our members have a turnover of less than $1 million. Mind you, at the other end of the scale we have members who have a turnover of a quarter of a billion dollars.

You also then have to go back to the genesis of the service systems as we know it. You will notice, particularly those of you in your electorates around the State, that there is a plethora of fiftieth and sixtieth anniversaries of disability services happening at the moment. That is because they tended to come out of the post-war era, not many dealing with those who came back, as in the US, with war injuries. It was the baby boom era when obviously a lot of babies were born and we had a group of parents right across the country, and it swept like a wave, who up until that point had been told, "You have a child with a disability. Put the child in an institution somewhere and get on with your life." They said no. The one I worked in at Tamworth was started by a group of parents. One of the parents who was involved in starting that is still the chair some nearly 60 years on.

The Hon. TREVOR KHAN: You cannot get away from it, Tamworth people are everywhere.

Mr MAHER: That started just as a playgroup in a shed at the showground in Tamworth. Today it is an organisation that cares for nearly 500 people with disability, it employs 300 people and it is, I think, a $20 million turnover organisation. That has grown out of what the parents did, without any government assistance or support for many, many years. Then there is the influence with your local member. That group had Ian Sinclair as their local member. They were in Government for a long time when most of this was happening through the Federal sphere. That is how you got funding into the sector in your services, if you knew the local member and he knew who to tap on the shoulder. We now have a more equitable basis for getting the funding. But when you come to the discussion around are there too many or too few, you need to take into account there is an incredible sense of ownership of these community-based service organisations.

The Hon. GREG DONNELLY: For my benefit and perhaps for the benefit of other members of the Committee, briefly, what is the process of becoming a bona fide registered body?

Mr MAHER: I have got no idea at the moment, I have to tell you. You have to meet your requirements to become an incorporated association. You have to meet the requirements of the charitable collections Act. It is basically the State legal requirement and the Federal ones for the tax office and so on. There are not too many new ones.

The Hon. GREG DONNELLY: Subject to following those steps, there is nothing pressing against a group of people or an organisation wishing to gain status as a registered body?

Mr MAHER: Absolutely nothing at all. Gaining status and obtaining funding from a government are two distinctly different things. At the moment I see with great interest and admiration groups of parents now getting together and wanting to start different types of services and new types of services. Government is talking to them and the department is talking to them. We encourage that. We also encourage them to look at what other services are around, possibly capitalise on the work that has been done and see if they cannot have some influence with existing services to get people to think in a different way. You cannot keep running a service that has board members that have been around for 50 years and expect that they are going to be receptive to the change that is needed today. But you also have to respect the work that those people did to get that organisation to where it is.

There is strength and benefit in some of the other matters we are addressing through the Industry Development Fund, not the least of which is looking at the opportunity of back-office support. Let the small services, of which the local community has a tremendous sense of ownership, continue on and operate, but let us look at how we can back them up and support them in back office by providing HR management, financial management skills, doing their acquittals back to the department and their recruitment services and getting their quality for them, and let them get on with doing what they are good at. It is interesting that we have a lot of support for that in the Industry Development Fund proposals.

Also interesting, probably in the last month I have been asked to address five groups of at least two boards to talk to them about how they would go about merging. So there are people out there thinking about it. But it is not the panacea; it does not solve everything. There is no point in merging two bad organisations in the hope of ending up with a good one. We do need to be working with bad organisations—and I do not believe there are any among our members. We need to be working with organisations that are struggling to help them get across the line. We will always facilitate people who want to talk to us about merging. We would not and cannot, because it is in our charter, go out and promote it. If they want to talk about it we certainly will assist.

The Hon. GREG DONNELLY: Does anyone else want to make a contribution on that point?

Mr MAHER: Did you want to talk about the one million?

Ms CASKA: Did you want me to go to your question now?

CHAIR: Yes, please.

Ms CASKA: It is referring to the chart that we put in on pages 9 and 10. That data came from ADHC's annual report from last year and essentially their data on that comes from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers from 2003. What we are trying to show in the graph essentially is that it shows across the regions that there are just over one million people with a disability in New South Wales. In the last financial year just over 5 per cent on average of those people received a formal service funded or provided by ADHC. National Disability Services is not an expert in the area of unmet need. I would start by saying that does not mean that that equates to the other 95 per cent out there knocking on our door wanting services. The things to consider in this space are firstly, as Jim Moore pointed out today, that our non-government organisations receive funding from other sources. So that is just the people receiving ADHC-funded services. There are fundraising sources and there is also supported employment that is funded through Families, Housing, Community Services and Indigenous Affairs [FaHCSIA] and then there is open employment funded through the Department of Education, Employment and Workplace Relations [DEEWR]. So that would take up quite a lot of other people as well.

Unfortunately, that data matching has not been overlaid. So we do not know about that. It is also dangerous to assume that the other 95 per cent of people, just because they have a disability that they need a formal service. That is underpinning everything we do moving forward. We certainly do not want to see a situation where people are surrounded by formal services and that is all they demand, that is all they know and that is all they need. Also the last point, again which Jim Moore alluded to today, the issue of data—I know you guys have covered it quite a lot and probably will continue to—is the crux of our sector. We do not have reliable data. We do not have a single data source from which we can predict the future. This has been acknowledged through the National Disability Agreement. There are two strands of work being carried out in New South Wales specifically to address that.

Mr MAHER: It is also fair to note that there are a lot of people receiving a service that is not funded. I can certainly cite the Spastic Centre and I can cite my old organisation in Tamworth, which provide services to people who do not receive a funding package from anyone. There are people who are receiving funding from the Federal Government which gets no record in the State environment, but also may be receiving a drop-in support service in their home from the local organisation service, which is not funded. The collection of data under this minimum data set, which is set under the COAG agreement, is pretty wishy-washy.

The Hon. GREG DONNELLY: A further issue that was covered this morning, perhaps not in a great deal of depth, was the ageing of people who are in a caring role and how we will deal with that. In other words, we have the situation of people who are disabled living longer and people caring for them living longer. I welcome your comments on that.

Mr MAHER: A national disability insurance scheme. This is the huge sleeper—the number of people. Again, if you go back to the services, which I am sure each of you would know, where there are ageing parents and extrapolate that across the country, we have an ageing population generally but we have people with disability, thank God, living a normal lifespan now and they have a normal life expectancy. But we still have very sad stories of parents who cannot let themselves die or have a rest because they feel there are inadequate services. It is moving towards finding more flexible models of providing support that we have been encouraged by in the last five years. But we have got a long way to go and there are still drastically inadequate funds to be able to meet that demand. That is why we have got to move to a system that addresses this. Whether it is a disability, whether people are having late onset disability because of age, whether it is ageing parents who need support, whether it is people with disabilities who are just growing to a happy old age in a natural way, there are insufficient resources. I do not think there is anybody sitting around a Cabinet table in this State who is going to commit to 14 per cent of the State budget going to disability. That is why we have to move towards the concept of a national disability insurance scheme.

That is what we are prosecuting. We are prosecuting a particular model. It is called an insurance scheme for no purpose other than to give people an opportunity to understand the concept in a broad sense. In prosecuting this we have formed a national alliance of Carers Australia, the Australian Federation of Disability Organisations and National Disability Services. It is this group that has employed Mr Della Bosca as the campaign director to put as a focus to the Productivity Commission the need to work with all State governments and the Federal Government to come up with a model that is going to work. As Jim Moore said this morning, the sector is going to look very, very different. I think it will take five years. Some are hoping it will take a lot less. I think we have to be very careful that we do not go too fast and get it wrong.

Dr JOHN KAYE: Mr Maher, you spoke about a $2.5 billion increase over five years, $500 million a year, on top of the existing $2.3 billion a year, taking it to $2.8 billion by 2015. Did you factor in the additional costs of the pay equity case or was that on top?

Mr MAHER: Can I say, first of all, I do not get the opportunity to go on record in *Hansard*, which is why I said $2.5 billion. I think someone needs to. I do believe it has been said before by a couple of people. That is not an ambit claim. I suppose it is to some degree.

Dr JOHN KAYE: It is now that you have said it.

Mr MAHER: As to the pay equity case, we would normally have expected the first year of round two of Stronger Together to have been in the forward estimates this year. The Premier did meet with us and explained that she was not prepared to have that fight just yet because of the pay equity case. We supported her position in doing this. There is no point in saying, "We will give you $2 billion over five years and find that a quarter of that is chewed up with the pay equity increase." We need to know what the number is and we need to then be able to have the Government look at all of the data before it before a number is arrived at. It is very easy to say these numbers: they roll of the tongue very readily. I would have thought that with the pay equity case taken into account that $2.5 billion-plus would be satisfactory, including the pay equity case.

Dr JOHN KAYE: That includes the pay equity case?

Mr MAHER: Yes. I would have thought it would be satisfactory, including it.

Dr JOHN KAYE: You talked about 47 per cent of organisations chewing up 4 per cent of the budget. You said that is evidence of duplication. Can you take me through the logic? Forty-seven per cent chewing up 4 per cent of the budget is evidence of a greatly diversified sector with very diverse sizes. How does that go to duplication?

Mr MAHER: It was a bad choice of words on my part. Duplication of back office or, if you like, inefficient use of back office. If you have a number of small organisations who are employing a chief executive, a financial person, a HR person and so on, it is not a duplication of the services they are providing. It is chewing up a lot of money in administration. If some of that administration was blocked together it could probably generate some savings. It is not about stopping those people from delivering those services; it is about facilitating them to be able to deliver them more efficiently.

Dr JOHN KAYE: So the duplication is not in the services they deliver?

Mr MAHER: No.

Dr JOHN KAYE: I understand that in some industries and sectors that form of duplication is dealt with by networking rather than by merging. For example, councils do this with their regional organisations of councils. They do not surrender any autonomy. When they agree on certain functions they get together to perform those functions collaboratively. There is, I am sure, and I am interested in your opinion, some benefit in a diversified sector. Some of those smaller organisations—I am thinking of one in particular—are remarkably responsive to the people to whom they deliver services in a way that perhaps large organisations would find more difficult to achieve. Can you comment on the idea of networking some of those smaller organisations to achieve economies of scale and scope while still maintaining that remarkable personal contact and flexibility?

Mr MAHER: I am absolutely supportive of that and if I have given any other view in what I have said I have misled you in the way I have said it. I think we are using different words to describe the same thing. We are talking about shared back office, however that is done, through networking. We are talking about having a formal capacity to approach people—rather than expecting groups to figure it out, particularly the small ones that are very busy doing what they are doing—and saying there is an opportunity for them and that the department is prepared to make an investment to provide a shared back office capability if they are interested in doing it.

Dr JOHN KAYE: To be clear, are you saying that is what you would like to see happen? ADHC would work with you to create this opportunity to share?

Mr MAHER: Yes. They are working with us. It is part of the industry development fund grant implementation plan.

The Hon. HELEN WESTWOOD: To continue on the same theme of a future with either fewer organisations or the sort of resource sharing that we have heard described, both you and one or two other witnesses today have talked about there being quite a different disability landscape in five or 10 years from that which currently exists. Clearly there is going to be a significant transition period. What preparation is being done through either your peak organisation or the various State and national departments by looking at models of service delivery or alternatives such as resource sharing that will deliver the efficiencies in the future disability landscape that we have all come to expect?

Mr MAHER: Other than those things that are listed in our industry development plan the key work that is being done is the national disability insurance scheme campaign. John Della Bosca will have a staff of about 10 people scattered around Australia who will be working with the different State governments and feeding into a central model. National Disability Services is setting up a national policy and research unit located in Canberra that will have about 10 people focusing on the issue that you are talking about. This is all about pulling together over the next two years as much information as we possibly can in the research phase and then spending the next three years working on influencing policy with the Federal Government and all the State governments because of the different way the world is likely to look if we end up with a thing called a national disability insurance scheme. The likelihood is we are going to end up with some sort of procurement authority that will buy all the services on behalf of whatever that pot of money is and how it has been arrived at. When you get to that point, should State governments be in the business of disability, should it all be outsourced, and do we keep the commercial operators out or allow them in? NDS has a very strong view of that. We cannot have somebody in there whose first obligation is to their shareholders. The first obligation has to be to the person with disability at the centre of the service system. We will work very hard to ensure we achieve that outcome.

The Hon. HELEN WESTWOOD: Are you sure Mr Della Bosca is of that view?

Mr MAHER: Yes. Not that I would want to verbal Mr Della Bosca.

CHAIR: We have run out of time. Thank you for giving evidence this afternoon. We will probably be in touch with you with some questions on notice in the next couple of days.

Mr MAHER: We are available.

(The witnesses withdrew)

ELENA KATRAKIS, Chief Executive Officer, Carers NSW, Level 18, 24 Campbell Street, Sydney, sworn and examined:

CHAIR: Would you like to make any opening comments?

Ms KATRAKIS: I thank the Committee for inviting me here today. We have provided a written submission, which probably covers pretty much all the things we want to say in detail. There are matters I would like to highlight. Carers NSW is the peak body for unpaid family carers in this State. We are part of the national Network of Carers Associations. The comments I want to make relate to carers' views about Ageing, Disability and Home Care services provided within the framework of the terms of reference of the inquiry.

Among the key points I would like to highlight are a couple that carers bring to our attention and the main concerns of carers in the State, which focus on the availability of supported accommodation or the lack thereof. While there are many good programs across the State funded by the department there is a high level of unmet need in the number of available places both in New South Wales and nationally. Carers NSW has a dual role: We receive funding from Ageing, Disability and Home Care as the peak body for carers, which enables us to do the policy and advocacy work that we do. We also receive funding from the department as a service provider. We deliver a number of programs. One in particular is an older parent carer program, of which we are one of 10 providers across the State, and we are involved in service delivery. We are also involved in an innovative care program on the mid North Coast called "My Plan, My Choice", which is trialling an approach in looking after 10 families by providing quite substantial packages, which seems to be making a real difference to families' lives.

As both a peak body and a provider of ADHC services we have found differences between the information provided to us through the head office of the department, where we have a very good relationship and are briefed regularly on different issues and they take our advice on matters, and the local and regional level where the information we receive can be quite different from region to region and can create problems not only for us but also for other service providers across the State. When you have got a program statewide there are different ways of delivering under different guidelines and interpretation of guidelines at the regional level. Also at the regional level there would be different involvement from the regional offices and staff, depending on how involved they are in the programs and things like that.

One of the other issues which I suppose I would like to highlight is around communication and expectation. There are families within the disability sector who have a very high expectation of what the department may or may not be able to provide in terms of supported accommodation, and particularly the last speaker mentioned in terms of ageing parents with adult sons or daughters disability and what their future may hold. The expectation lies around what will be available. Again it comes back to communication at the local level and what is communicated to families.

Families tell us about things like being on lists for accommodation and then contacting the department and there is no knowledge of the list that they are on, or trying to contact the department and finding that they have to update their details on that list every year. This is of great concern. Families think that they have got their names on a waiting list and then find out years down the track that it does not exist, or something that may have existed five or ten years ago no longer exists today. They put their name on that list thinking that their problems will be solved down the track and that that will address their concerns. Whether the list exists is always a matter for debate but it is about expectation about communication. If programs change or things are no longer funded families and carers and people with disabilities need to be aware of those changes at that local level. Those are things that impact on service delivery on carers within this State.

One of the very positive things that ADHC has been involved in has been the focus on young carers. "Young carers" mean somebody under the age of 26 years of age, so young people and young adults caring for possibly an adult sibling with a disability or illness. In the past couple of years ADHC has decided to focus more on that. We received funding from ADHC for young carers and they have set up a higher level interagency committee across government agencies which is starting to focus on this issue, which is really important to get the Department of Education and Training and things like that engaged in young carer issues. So there has been some movement there, which we are very pleased to see, but the funding around young carers within this State and nationally is very poor. They are probably the things I wanted to highlight. Everything else is written there. I am happy to take questions.

The only other thing I would say is around contracts and funding and competitive tendering. When you are delivering a program and you set up local offices and then you may not be successful in retendering, although you deliver a good service and have been told you deliver a good service and meet all your KPIs and outcomes. You then may not win the tender because someone can write a better tender than you or can put bells and whistles and whatever else on it. It can create problems. That is something that is common across government, having just found out on Friday with another agency that we are going to shut seven of our offices across the State. On Friday and today I spoke to just over 20 of my staff who are going to lose jobs. It is really a different funding stream but it impacts on our service delivery with Ageing, Disability and Home Care. We obviously shares costs across programs for those backroom kind of things, infrastructure costs and things like that. It creates a massive problem across the board. The impact on carers and the people that are the subject of where the service is being delivered often are not taken into account when those decisions are made.

And the transition in and out of programs—by the time you transition into a program and a new providers comes in and starts a program there is obviously a time lag, and the impact that that has on your service receivers, service providers, the community and in terms of cost savings and whether that is a good use of funding also is a concern for us.

The Hon. MARIE FICARRA: Does that make Carers NSW more reluctant to enter tendering either solo or with another organisation in the future given that experience?

Ms KATRAKIS: It does because just with this other program, as I said, it is not an ADHC program but it highlights these kinds of issues. It is something that is evidence-based that we, in fact, commenced many years ago with respect to first funding within the State for this particular program. It is not to say you want to be tested; it is not about you get funding, you get funding for life. Obviously, if you are doing a good job and you are meeting accountabilities there is no complaints, all of those kinds of issues. It does make you step back because now within what is a very short period of six to eight weeks I have to close seven offices and have twenty of my staff step down.

The Hon. MARIE FICARRA: In your initial report you referred to carers packages for families on the North Coast and a successful initiative there. Will you elaborate on that?

Ms KATRAKIS: It is "my plan, my choice". There are 30 families across the mid North and far North Coast and out to Tamworth. Carers NSW has 10 families on the mid North Coast. It is a consumer directed care package where there is funding of up to $50,000 per family for things I suppose outside the norm of what is available within existing services. So it is really to look at quite different packages of funding where the carer—it is focused on the carer and this could then apply to the care recipient—to look at different ways of supporting their family and those carers in looking after that person.

Why it is a different model and how it kind of works is that Ageing, Disability and Home Care provides the role of the support planner and they actually recruited the families into the program. A lot of organisations, including us, nominated families into that. So ADHC actually picked the families. The NGOs within the programs on the mid North Coast are there as support intermediaries. What that means is that ADHC works with the family and develops up a support plan about what might be possible, whether that is construction of a pathway into their home because they have someone with a disability, they live in public housing and the person with a disability has not been able to access the home without assistance because there is no pathway and there is an overgrown garden.

They build approved pathways and other supports and things like that. The support intermediary, say Carers NSW in this instance, works with the family to then purchase those supports, to get those supports and equipment or whatever it might be to meet those needs and to meet the needs within the support needs. Why it is a good model is that the onus is not on the carer to have to navigate that service system. When you are in a rural or a semi-rural area where there are fewer services often it is difficult if you are given money as the carer—you know, a lot of consumer directed care packages aim that funding direct at the carer—but the carer then has to find the service, look for all those things.

The support intermediary is able to source those things and we take that load off the carer to then provide and look for those programs. It is a small program. It is going to be the subject of an action research evaluation which ADHC is looking at at the moment. I think they have engaged a group to undertake that research and it is having some really good outcomes. But for others an hour a day may be available whereas they need something else at a different time. Things like respite for, say, working carers—an issue that has been raised with us has been working carers with spouses with young onset dementia, and with the rapid deterioration in that person, being under 65, trying to continue to balance work and care and only being able to get respite for a couple of hours, that does not fit in and does not enable them to continue to work.

The Hon. TREVOR KHAN: Could I take you to the fourth whole paragraph on page 5? The first sentence reads, "The evidence suggests that the amount of government funding in real times for respite per service user has decreased". What is the evidence, if I put it in that broad term?

Ms KATRAKIS: In terms of—

The Hon. TREVOR KHAN: What is the foundation upon which that sentence is based?

Ms KATRAKIS: I will have to look at what the reference is. It goes back to the reference from the report, which is at number 12, which is the Australian department of health and ageing, the HACC program annual report, so based on the numbers there and articulated within that report that, in effect, while the funding has increased the number of users has also increased. If you do the maths—

The Hon. TREVOR KHAN: You divide X into Y—

Ms KATRAKIS: It is less per service user.

The Hon. TREVOR KHAN: But that relates to Federal government funding as opposed to State government funding?

Ms KATRAKIS: There is HACC funding that comes to the States as well. It is a national-funded program but it is also delivered through the States.

Dr JOHN KAYE: I wanted to go to the issue of competitive tendering with you and I wanted to put to you the proposition that the two key concerns you have with competitive tendering are the uncertainty that it creates in your future funding and, hence, the inability to aggregate resources to put in one place to get an ongoing program and an ongoing infrastructure to support that program; secondly, the nature of the competition itself, being a paper-driven competition that, as you put it, the people who can write the better application package are more likely to win rather than those who deliver the better service on the ground. Is it fair to say those are your two key concerns with competitive tendering?

Ms KATRAKIS: They are my two key concerns. Just because people might write a better tender does not mean they cannot deliver the service, but you have larger non-government organisations able to outsource the development of a tender—even a professional writer—all those kinds of things that are so far removed from the actual service on the ground. But they can tick all the boxes in a way that maybe a smaller non-government organisation cannot. It is not an even playing field.

Dr JOHN KAYE: It is an uneven playing field not only on the capacity to write tenders but also consequently on the size of the organisation and competitive tendering will tend to discriminate against the smaller organisations?

Ms KATRAKIS: It can be, yes.

Dr JOHN KAYE: Many of which might be quite excellent in terms of their client focus and their capacity to deliver a highly responsive service?

Ms KATRAKIS: That is right.

The Hon. TREVOR KHAN: Can I just interrupt? What is the alternative to a process of a competitive tender?

Dr JOHN KAYE: That was exactly my next question.

Ms KATRAKIS: Some of the discussions with ADHC around future funding have been talking about how you will have a set lot of funding as an organisation with an agreement around programs. How you spend that money and deliver that program is up to you. The other thing—which takes it off a bit from competitive tendering and the issues—is where you might have surpluses at the end of the financial year and you put in submissions to utilise that funding back into the program and how to do that, but you cannot utilise the surplus funding until you get approval from the department.

We can have surplus funding year into the next year to the next year. I have been with Carers NSW for four years. Over that four-year period we have got submissions in that have never been approved. So you have funds sitting there that you cannot utilise, that are sitting there gaining interest until we can have the go-ahead to utilise those funds back into the program. I know I have taken that off the track a little bit.

The Hon. TREVOR KHAN: Go back to the competitive tendering question.

Ms KATRAKIS: I am not sure what the answer is. I do not know what other models there are. Yes, you still need accountability—absolutely—and you need surety that you are delivering a good service. But often things start off with pilots—two-year pilot programs. Will they fund into the future? You enter into these things knowing that they are a two-year pilot, absolutely, but then they go, "It's pretty good. What will we do? We might do an evaluation, have a look at it", and then you are temporarily extending the contract, temporarily extending staff—staff that have mortgages; carers that do not know whether their service will continue into the future. So your service drops off a little bit, staff start to go. There is still no surety. Then it is up and it is a case of, "Yes, we are going to continue to fund it". It creates a level of uncertainty for everybody and it does not provide for continuity of service.

The Hon. TREVOR KHAN: But that is not really quite the issue with the alternative to competitive tendering. That is contract administration, but where you are dealing with any contract that comes to the end of its time and has to be renewed how do you deal with it other than by a tender process that gives service providers the opportunity of putting in a tender for the service?

Dr JOHN KAYE: I guess the question that I am asking then—

The Hon. TREVOR KHAN: If you are going to NGOs operating the system then a competitive tendering process is fundamental to it.

Dr JOHN KAYE: The question I wish to put to the witness, to pick up on Mr Khan's point is: Is it the fact that the act of putting something out to competitive tendering necessarily attracts in a lot of larger organisations whereas there might be other ways of perhaps having a smaller field of alternative providers rather than an open competition, perhaps a controlled competition—

Ms KATRAKIS: A select tender process where you are going out to a select group of specialist organisations within the area. Carers has had much more press or has been on the agenda a lot more over the last couple of years. There has been a Federal inquiry, there have been things happening with the National Disability Insurance Scheme—there is a whole range of different things that have focused on carers. There are a lot of organisations that think, "I want a piece of that action. I want to be in the carer realm", and so put in, and they are not necessarily carer focused. I am just using Carers as an example.

Dr JOHN KAYE: Let us focus on Carers. What you are saying is that the nature of the competitive tendering process is drawing organisations in who might not have specific expertise but the nature or the way the tendering was written allowed those organisations to compete against organisations that were already in the tendering activity?

Ms KATRAKIS: Yes, and if you have been performing poorly then that should be brought to your attention throughout the course of your service delivery, not to just be defunded at the end of the time without a clue why you have been.

Dr JOHN KAYE: If the objective is to minimise the incidence of poor performance is what you are saying to us that there are other ways of doing that than through competitive tendering?

Ms KATRAKIS: That is right.

Dr JOHN KAYE: By assessing the quality of service delivery?

Ms KATRAKIS: That is right, because at the end of the day the non-government organisations are really businesses as well. They have got to survive. If you are an architect and you are contracting or tendering to do whatever building, you know that there is a time limit, and that building comes and then you have got another tender coming in. Yes, there is a time limit, but where there are programs that are continuing into the future and they are recurrently funded and then they go to an open tender process it can create difficulties. I do not know what the answer is but I think there has to be a better way, and obviously this is very close to me at the moment, so maybe I am just particularly—

The Hon. TREVOR KHAN: Wounded.

Ms KATRAKIS: Wounded.

CHAIR: John, do you want some elaboration to the answer to the question as to incumbency versus new tenderer and the obvious added costs of incumbency?

Dr JOHN KAYE: Yes.

CHAIR: Can you elaborate on that?

Ms KATRAKIS: It is not cost-effective because if you are set up you have got the relationships, the MOUs and things like that to operate your program at the local level; you have got the staffing; you have got your office space; you have got people with mobile phones, computers, et cetera, et cetera.

CHAIR: On-costs?

Ms KATRAKIS: On-costs.

CHAIR: Staffing on-costs?

Ms KATRAKIS: On-costs—it all adds on.

CHAIR: Training issues?

Ms KATRAKIS: Training, identifying carers—the client base. You have got to go out there; you have got to start again. All your promotional material; all those things have to change and relationships redevelop. We have been delivering that program for six years.

CHAIR: So you may have staff that are actually accumulating long service leave, annual leave—sick leave even? People do get sick.

Ms KATRAKIS: Yes, we have got all those added costs, that is right—long service leave if they have been there for a period of time.

CHAIR: As the incumbent you are at, what, a 30 per cent disadvantage to a new starter?

Dr JOHN KAYE: A financial disadvantage.

Ms KATRAKIS: That is right. This particular one I am talking about is not funded but it can easily apply. They extended it for three months. Halfway through that three-month extension now they have told us we do not have it so we have got less than that period of time to wind down with the new providers starting up from 1 October. But they are not going to be operational on 1 October. We will close on 30 September but then they will take another three months to be operational.

CHAIR: And will they source some of your staff?

Ms KATRAKIS: I hope so.

CHAIR: As new starters?

Ms KATRAKIS: That is right.

The Hon. HELEN WESTWOOD: I am not sure if you were here earlier and heard evidence from some of our other witnesses but much of what we have heard today has been about Stronger Together, the changes in the introduction of that policy framework, and also where we go from here leading to the idea of a national disability scheme. I am just wondering whether Carers NSW has a view. What is your sense of Stronger Together? Has it improved services to carers and to the organisations that you deal with?

Ms KATRAKIS: I think it has. Within Stronger Together, and in one of these sub-documents within that whole sort of package of reforms was the announcement of the New South Wales Carers Action Plan. That came in and was launched, I think, in March 2007 and that is a five-year plan. That was good and it signalled that the issue of carers did not sit just with ADHC or with Health, that it sat and needed to be responded to across a range of government agencies—Housing NSW, the Industrial Relations Commission, a range of different agencies. That has been good in terms of those other agencies identifying not only carers as clients but also carers within their own workforce and how they might address those needs and be a bit more flexible. Those things have been very positive.

There are five key priorities within the action plan. That has, I suppose, provided a platform to get some of those caring things underway within the State. It has gone a bit of the way and agencies have responded differently but, again, there was not a huge amount of funding that was put towards some of those agencies. Some of them got small grants to do some very small projects. Our regular peak funding received an increase at that time in 2007. Our peak funding was included as part of the action plan. As our peak funding we deliver education and training to carers and service providers about carers. We provide policy advice to government around caring issues. We comment on submissions and other policy documents and directions that governments are going in. All those things are funded through our peak body. There was not a really huge amount of additional funding within that. Stronger Together gave recognition of carers. There is funding around respite and supported accommodation but, again, it is the level of that funding and the number of supported accommodation places, but we do not think it is enough.

The Hon. HELEN WESTWOOD: Does Carers NSW have a view on the proposal for the national disability insurance scheme? Do you support that?

Ms KATRAKIS: Yes, we support that. Carers Australia, the national body, is in an alliance with the former speaker from NDS. We are certainly supportive of that. A lot of our members are supportive of that. It is around that long-term care and support and about funding for that care and support. What needs to happen though is that the service system needs to be there. There needs to be services to meet their needs. It is kind of a bit like the "my plan, my choice" we were talking about before. You can have the money and the package but you have to have the service system out there that is going to meet those needs. Yes, we absolutely are supportive, but the service system has to come along with that.

The Hon. HELEN WESTWOOD: Is Carers NSW part of the disability services sector? Do you see yourself as part of that?

Ms KATRAKIS: We do. We work with carers of people with a disability. A lot of our programs are disability focused on carers of people with a disability. We see ourselves as part of that sector.

The Hon. HELEN WESTWOOD: You identify some areas in your submission, such as the specific needs of Aboriginal people, people of culturally and linguistically diverse backgrounds and the needs of gay, lesbian, bisexual, transgender and intersex people. I get a sense from your submission that you think ADHC has not really met the needs of these groups as well as it may be meeting the needs of other groups within the disability community. Can you add to that?

Ms KATRAKIS: Yes. Responding to culturally diverse carers is very difficult. Not that you want to have a parallel service system, but you really need to look at how those services are identifying carers and care recipients are engaging. It has to be culturally appropriate and obviously there needs to be funding to go to that. ADHC has funded us to translate facts sheets and do all that sort of thing. It is part of the answer, having information in relevant languages, Aboriginal brochures for the Aboriginal population and things like that, but it is about getting into the communities and really working with those communities. A lot of culturally and linguistically diverse communities do not even have a word for "carer"; it is a different concept. It is about looking at what that service mix might be. Sometimes a brochure or an Aboriginal-looking brochure about how to get services is not enough; it needs to be more at the coalface and to have appropriately trained and responsive services on the ground.

With the older parent carer program that we are funded to deliver by ADHC there is a separate component that is Aboriginal specific. It is half the funding level of the generic program and the guidelines are different in terms of age and things like that for Aboriginal people and families. We have seen a lot of success within that program through not only just employing Aboriginal people because we have also employed non-Aboriginal people to work in that program, but to have some targeted responses and to really work within the local communities to work and partner with other Aboriginal and culturally and linguistically diverse providers to really work with different models of service provision to those different communities. There are pockets of good examples out there. It needs to be more across the State.

The Hon. GREG DONNELLY: I apologise for being absent earlier and hope my questions are not covered by those previously asked. On page 6 of your submission you are somewhat critical of ADHC's process, particularly lack of timeliness in the evaluation of the support coordination program for older carers. Could you reflect on that and perhaps put forward how that process can be improved?

Ms KATRAKIS: This is the older parent carer program I mentioned?

The Hon. GREG DONNELLY: Yes?

Ms KATRAKIS: It started as a two-year pilot. Six months out from the end of that pilot I and the other providers, of which there is about 10 across the State, were kind of asking whether this is going to continue or not continue? There had been talk of an evaluation but there had not been anything. Then the evaluation kind of came in quite quickly.

The Hon. GREG DONNELLY: This was six months out?

Ms KATRAKIS: Yes, but closer to the end of the funding, so closer to June than to January. The evaluation was quickly done and then there was a decision that was positive that it was then recurrently funded but, again, there was that anxiety and uncertainty created about what was going to happen. We knew it was a two-year pilot—you set up infrastructure and ran off other programs, which was okay, but ended in two years; we can deal with that. But will it end, will it not end? If the evaluation had occurred earlier or had occurred as part of the program as it was being undertaken then there would not have been that level of uncertainty. Rather than doing a quick evaluation to get information and, I suppose, an evidence base to decide whether to continue to fund, it would have been better to have done it as the program was developed, and along the way rather than quickly at the end. With the "my plan, my choice" on the North Coast, when we signed up to that we were told that the action research would happen along the way from the start of the program. We thought that was really good. That has been funded only for the first 12 months of that program. That 12 months is almost over and they engage someone for that action research, but it has not really commenced. Again, it is not across all the regions.

The Hon. GREG DONNELLY: My next question relates to a subject that was touched on earlier today by other witnesses. It is an underpinning theory behind the provision of services of the movement towards self-managed or individual-based funding notions, which articulate greater flexibility for service provision. What are your organisation's thoughts about that? Have you any comments in regard to that?

Ms KATRAKIS: I think I made some comments about the "my plan, my choice" program before, which is a consumer-directed care package. It is about choice for carers and families. Giving funding in that way to a family will work for some families but not for all families. It needs to be a component that is part of a suite of choices of how to provide support. Some families do not want to navigate the service system or purchase services themselves or do that. They would rather have those services come to them. Whether that is older or younger people, it is not necessarily an age-related issue, but it is about choice. You then have a range of different ways of delivering services or carers purchasing services so that there is choice within that.

The Hon. GREG DONNELLY: Could I be the devil's advocate and ask has there been, could there be, the possibility of people making choices that ultimately do not turn out to be choices that perhaps work best for them that otherwise might be available through another stream or method of providing services to them? If so, what is the way of unravelling or unpicking that choice and providing the capacity to go back and exercise another choice?

Ms KATRAKIS: I agree that people do not necessarily make the right choices or people make a choice based on something and it does not work out. Often families employ other family members as part of the self-directed care packages. That also means you are taking what was an informal support of Billy coming to mow the lawns but then paying Billy to mow the lawns. Then he is no longer is part of the informal support network; he is part of the formal support network. That changes the dynamics and all of those things. When a family is employing another family member there can be huge issues with that. With "my plan, my choice" we are that support intermediary and we carry that risk for the family. We work with an employment agency. We do not employ the family member directly but we employ them through an employment agency. If there is a risk or something goes wrong and Billy does not work out you have an employment agency there so you still have some safeguards around that. That model again is one component or example of a model. That is why that model is a bit different, because it takes that burden off that choice and the carer making that choice for themselves. That will work for some, but with others there is that protection as well.

Dr JOHN KAYE: But that will add cost?

Ms KATRAKIS: It will, yes.

Dr JOHN KAYE: Employment agency costs?

Ms KATRAKIS: Yes. Within that example we have been able to negotiate very reasonable low rates so that it does not take too much off the package for the family.

CHAIR: Can you elaborate on the issue of a family member employing another family member and becoming an employer-employee relationship and all the associated responsibilities of insurances, workers compensation et cetera of becoming an employee of a family member?

Ms KATRAKIS: From what we have seen, it can be absolutely fraught. That is why the model we are working in is able to remove that onus from the family, where it can be extremely problematic.

CHAIR: It can also be extremely expensive if the family member has an accident?

Ms KATRAKIS: That is right.

CHAIR: And they are not insured?

Ms KATRAKIS: That is right.

CHAIR: All sorts of issues could arise. I would have assumed that that sort of arrangement would be not allowed?

Ms KATRAKIS: Within this package it is, but we have worked around that with the employment agency. There are other programs that we are not delivering where that is part of the package and there are some models in Queensland where they very much are giving the dollars to the family and the family member is very much the employee of those other family members.

CHAIR: On face value I see that situation as setting the person with a disability up to fail and be put in a position where they could be liable for quite substantial expenses. I would assume that there would be safeguards against that? I am not suggesting that they cannot have a relationship where they choose who provides their services, but I would have thought of that establishing an employer-employee relationship should not be allowed?

Ms KATRAKIS: It can be difficult and there is a lot of evidence from the United Kingdom around problems within those sorts of consumer-directed care packages in that way where they employ family members. The model we have and what we are working on works because we defer that risk to the employment agency. Yes, there is a small cost that comes off the package for the family, but we think it is worth it.

CHAIR: A required cost?

Ms KATRAKIS: Yes because ultimately the other cost would be much greater.

The Hon. HELEN WESTWOOD: Today we have also heard a little about the adequacy or inadequacy of the complaints handling mechanism. I wonder whether Carers NSW has a view on that and whether carers have complained to you because they have been dissatisfied with the service. Do they know how to complain? If they have complained, have they been satisfied with the process?

Ms KATRAKIS: We would advise them how to complain and how the process works. We do get parents coming to us about ADHC, at both regional and head offices. Whether it is about a complaint or just about trying to access a service, they do find getting the information incredibly difficult. With regard to information around complaints handling, there are differing views and outcomes there. We have had some that have had positive experiences and some that have had very negative experiences and feel that it only takes an issue so far, so they go away unsatisfied. We would refer people to the Ombudsman and other areas for that. There are mixed views.

With regard to core services, sometimes ADHC may fund a service and a carer or carers might think that that service is from ADHC. There might be something that is subcontracted. Say it is Carers NSW, or another service provider. Often the complaint is not to ADHC; it might be to another service. Sometimes it is about navigating that service system and that kind of thing, but carers do not know where to go to make the complaint because they are not really sure who is delivering the service.

CHAIR: Thank you for your appearance today. Your evidence has been very helpful and informative. We may wish to send questions on notice to you over the next 48 hours.

(The witnesses withdrew)

(Short adjournment)

CHRISTINE REGAN, Senior Policy Officer, Council of Social Service of New South Wales, 66 Albion Street, Surry Hills and

SAMANTHA EDMONDS, Deputy Director Policy and Communications, Council of Social Service of New South Wales, 66 Albion Street, Surry Hills affirmed and examined:

CHAIR: Would either of you like to make a brief opening statement before we proceed to questions?

Ms EDMONDS: The Council of Social Service of New South Wales [NCOSS] provides independent, important policy development advice and review, and plays a key coordination and leadership role for the non-government social and community services sector in New South Wales. For our submission NCOSS has drawn on the expert advice of several of our policy forums: the New South Wales Aboriginal Community Care Gathering Committee, which comprises Aboriginal and Torres Strait Islander workers and community members in community care and disability; the New South Wales Home and Community Care [HACC] Issues Forum, which comprises representatives of relevant non-government statewide consumer and service provider peak organisations and networks, statewide local government organisations and HACC development workers; and the New South Wales Aged Care Alliance, which comprises over 25 organisations concerned with the adequacy and quality of aged care and other services, as well as healthy ageing and older people in New South Wales.

NCOSS acknowledges the amount of work that ADHC has committed to providing services and supporting older people and people with a disability. In our written submission NCOSS has made comment under each of the terms of reference, but we would like to emphasise in our statement that ADHC has undergone a series of major changes since its inception, which diverts focus away from the people who are requiring these services towards coping with internal and structural implications for operations and management. The system is still in crisis and, while Stronger Together has improved the adequacy of the disability support system since 2006, NCOSS contends that it has been a good first step only. The current process results in managing emotional turmoil by providing temporary bandaid stopgaps, which often become permanent as competing crises arise.

We also acknowledge that there is continuing and growing unmet need for older people and people with disability and there is also ongoing undermet or unmet need—that is, people receive a service but it only partially meets some of their need. We thank you for this invitation to attend the hearing today, and we look forward to further assisting the inquiry.

The Hon. TREVOR KHAN: I refer to page 3 of your submission. Firstly I will deal with the HACC issues forum. Has the HACC issues forum had the opportunity to meet since COAG's decision to change the funding structure of administrative arrangements for the HACC program?

Ms REGAN: They have. They met in June.

The Hon. TREVOR KHAN: Are you able to tell us how the forum responded to the changes?

Ms REGAN: Yes, I am. Originally both the HACC Issues Forum and the Aged Care Alliance were not for a major split in the Home and Community Care Program because it is a major, major structure and it was not clear at the time why the decision was made. The Aged Care Alliance, in particular, put out a position paper on the issue, which we used to inform the Premier, who was Premier Iemma. That was the first time it came up, in 2005, and then we resubmitted it when it came up again—

The Hon. TREVOR KHAN: Was Morris Iemma Premier in 2005?

Ms REGAN: Yes. When it came up again the advice still stood. The reason being that it was not very clear—

Dr JOHN KAYE: Morris Iemma was not the Premier then; it was Bob Carr. Bob Carr did not go until 2006.

Ms REGAN: It must have been 2006 that we put in our submission. It says 2005 on our document and that we presented it to Premier Iemma.

The Hon. TREVOR KHAN: Morris Iemma would not have been the relevant Minister at that stage, would he?

Ms REGAN: No, he was not.

Dr JOHN KAYE: Morris Iemma was the disabilities Minister in 2005.

Ms REGAN: The reason we came to the position was that there was just a decision. Would it not be a good idea to split HACC into aged care and disability, because then people would be clear about who was funding aged care and who was funding disabilities? HACC had been operating since 1985. Had it been clear at the outset that the decision was in order to create improvements for older people and people with disabilities, where those improvements were guaranteed on the ground, there would not have been any opposition to a structural change in home and community care. Given that that was not clear at all, until the decision in April this year when the decision was accompanied by, "And we intend that this will improve services for people", we felt to some degree that it was a bureaucratic decision rather than a structural decision to create real change. Given that we have it now, though, the HACC issues forum is keen to see how it will play out. They are certainly very, very concerned about some of the potential dangers.

One of the concerns is that in New South Wales we would contend that HACC has a very strong grass-roots connection within the community. There are HACC forums throughout the State. They are easily identifiable—they are for people with disabilities and older people and their carers—and it does create a bridge between disability services and older people's services. We would hate to see that lost under a split. We do know that under the split services that provide to people aged 65 plus will become aged care services, and services they provide to people with disabilities aged under 65 will become disability services. We are not sure how they will reintegrate. We are concerned for some population groups. One of the population groups is clearly people with disabilities who are growing older. We know that under the terms of the COAG communiqué once a person with a disability turns 65 the Commonwealth will pay for their services wherever they are. What we do not know is whether they will pay at the same rate that disability services are being paid or whether they will pay at aged care rates. We do not know how the industry will evolve—

The Hon. TREVOR KHAN: I am sorry to interrupt you. In terms of the difference in the rate of pay, is the rate of pay for a disability service higher than that for an age care service?

Ms REGAN: Usually it is. There is no such thing as a rate for disability services. Basically, if you are a person with a disability who is in a group home there is a historical fact about how much that has cost and how you have gotten into that place where there are identified levels for services in aged care. If you are in a high-level residence you get certain rates; if you are in a low-level residence you get certain rates; if you are on a community aged care package you get certain rates. It is not exactly the same. In disability, you are not actually assessed for a particular rate of service but, rather, for the service, and then depending on your need. If you have a couple of high-need people in an ADHC group home and a couple of low-need people the whole house will be costed rather than per person.

CHAIR: What about where you have a mix of ages?

Ms REGAN: That is the same; it just depends on what degree. At the moment people are just in ADHC group homes. For example, there might be four together; there might be a mix of ages over 20 to 30 years. The people who are a younger age might have fewer needs, but because of the staff ratio in the house they will be there to meet the highest needs of the house, so everyone gets that kind of support. It is not an individualised support yet. Independent plans are set. If you are within the house you will have an independent plan, but it is not funded or managed in that way.

The Hon. TREVOR KHAN: I interrupted you when you were going through a list of issues. Are you able to pick up on where you were up to, or have I destroyed your train of thought?

Ms REGAN: No. We are also concerned for Aboriginal and Torres Strait Islander people under the system because it feels a little bit like an afterthought, and also for culturally and linguistically diverse people and how they fit in. There are some concerns at the moment about people with disabilities under the new system because HACC provides the in-home support-style services for people with disabilities. In New South Wales about 20 per cent of the HACC population are people with disabilities; maybe a little bit lower. It is one of the lowest States for people with disabilities. However, figures show that the per capita rate spent by HACC on a person with a disability is much higher. So, while there are fewer people using it on a per capita rate, they tend to use more of HACC.

It is also NCOSS' contention, which is purely anecdotal at this stage, that people with disabilities who use HACC tend to not also use the disabilities specialist system, under the forms of support available under disability services. They are more the in-home support people who are very much home-based. We worry about being able to provide in-home support services as a new service type through the State when HACC splits off, but there is time to sort it out. So some of these safeguards and some of this speculation are still working through.

The Hon. MARIE FICARRA: Ms Regan or Ms Edmonds, on page 5 of your submission you raise concerns—and we have heard it from others today—that, despite the additional funding and as part of Stronger Together, disability services are lacking across the board in terms of inadequate service provision. How do you believe this Committee, in making our recommendations, should address that for the future?

Ms REGAN: As Sam said in her opening statement, we think Stronger Together is a very good first step. It is the first designated funding to do creative and capacity-building disability services in a very long time. There has been money streaming into disability services in the past 15 years or so but the number of new services bought for that has been very small. For example, for a doubling of the DADHC budget in disability we got less than a 19 per cent increase in the number of people using disability supported accommodation. So really it was more about bringing the services and standards up to date rather than increasing the number of people who could use them.

We are now into a stage where we really need to accelerate the number of people who are using disability services or have access to disability supports. A really good example of the unmet need is that—as I think I explained in the submission—when Stronger Together finally delivers, with some of the promised Commonwealth positions, just under supported accommodation, New South Wales will have benefited by about 1,400 new places since 2005. That is a good increase. But in 2005 the Australian Institute of Health and Welfare said New South Wales needed, at crisis, 7,300 places, but more probably 10,400 places.

So while we are grateful for 1,000 places it is really difficult to be over-the-top grateful for when we needed 10,000 in 2005 and by 2012 we will receive 1,400. The 1,400 places need a little analysis too; that is, 990 under Stronger Together plus extras from the Commonwealth National Disability Strategy. Of the 990, 640 places are going to people already in the system. They should receive those places, but that leaves only 340 or 350 for people who are now living in the community. That is where they are feeling the need, and that is where the 10,000 places will come from. This is a very small number of places.

The Hon. MARIE FICARRA: Do you have an estimate of how much funding would be required to meet the current undermet needs?

Ms REGAN: Not completely. We focused on just a couple of areas. We certainly focused on disability supported accommodation. Although we were pleased that Stronger Together met and exceeded its targets, we feel that there should have been better investment in some other areas, some of the weakest points, one being devolution. In New South Wales 1,400 people still live in very large disability institutions, and they need to be out.

Dr JOHN KAYE: Fourteen hundred?

Ms REGAN: Fourteen hundred.

Dr JOHN KAYE: These are the old style institutions?

Ms REGAN: Yes, they are.

CHAIR: You are not suggesting that those whole 1,400 for some reason can live independently in the community?

Ms REGAN: I am saying yes, they can, but only with support. They are in very large hospital-style institutions. In the sort of house that you and I would like to live in, but with appropriate support. Some will need high support and they should have it.

CHAIR: How are people being trained for those places? I am visualising the number of examples I have received, where people have come out of institutions needing high care. They have gone into establishments where the carers are not trained in any way, completely untrained. In many ways they do not know how to deal with the circumstances and situations in which they find themselves. Anecdotally, a lot of people have told me that that is a real problem.

Ms REGAN: I think you are right. Our reaction to that is yes, training, but you also get untrained people in very large disability institutions. What you do not get in a local house that you do get in an institution is because you have shared staff and very large group style services. If something happens that attracts staff to a particular episode or incident there is lockdown. You do not get that in a local house. The most people the staff will go away from would be three or four rather than 20 people locked in their rooms for a number of hours. Those kinds of things you and I would be very unhappy with. If it is unacceptable for you and me it would be unacceptable to others. Also, it is about the style of support that those people would receive. It is absolutely about training, absolutely about staff, but for some people it would be more appropriate to be in very small groups, or in very specific groups of people rather than just a group home being the answer to institutions. We know that is not true. We know also that there are quite a number of people with lower support needs.

CHAIR: It is not only group homes. People are in flea-bitten accommodation and are being exploited.

Ms REGAN: Exploited?

CHAIR: Yes.

Ms REGAN: I suppose I could commend you to a new view that has just been released, *A Place to Call Home*. It has been issued by Disability Enterprises and it shows a group of families whose adult children lived in a disability institution in the mountains. It shows how the families started off being very resistant and how they ended up with much better services in much smaller groups.

CHAIR: I am not suggesting that does not happen. You are painting a rosy picture of deinstitutionalisation, which is not the experience of a lot of people.

Ms REGAN: It is the experience of most people. I absolutely agree that for some people that experience has been awful, as always with any change. We need to sort it for those people rather than blame the system. Rather than saying that this has been a bad solution we should say the way we did it was wrong. Perhaps the solution is right but we need to have done it better.

CHAIR: That may be the case. The outcome is the same.

Dr JOHN KAYE: Would you like to make it clear that you are talking about disabilities and not mental health cases?

Ms REGAN: Absolutely.

Dr JOHN KAYE: There are very different outcomes in deinstitutionalisation between the two.

Ms REGAN: We are talking about people whose primary disability is physical, intellectual, cognitive, sensory, brain injury, and dementia; not people whose primary disability is mental health. We are not talking about mental health patients, although we must identify that many people with disabilities have a co-morbidity with mental health issues.

The Hon. TREVOR KHAN: You identified 1,400 people living in those circumstances. To be honest, that came as a surprise to me. Are you able to identify where those people are, in what sort of number in each institution?

Ms REGAN: I can get those figures for you, yes.

The Hon. TREVOR KHAN: It does not have to be precise, but I was not aware that that was the case.

Dr JOHN KAYE: I thought Richmond got rid of all that.

Ms REGAN: When Faye Lo Po' was the Minister—

The Hon. TREVOR KHAN: This is not a political point. I was not aware of it. I express my ignorance. I want to know whether the witness can identify that.

The Hon. HELEN WESTWOOD: I make the point that this is about resourcing. Richmond talked about resourcing adequately so that the transition could occur. And that did not happen. I am interested in the area of unmet need. That was spoken about this morning, and your first recommendation refers to unmet need. Specifically, you mention the release of a report in 2005-06. Is NCOSS aware of any method of quantifying numbers that is reliable within the Australian jurisdiction? Are you aware of any overseas jurisdiction? This morning the Committee heard that there are not reliable methods to determine or quantify the number of people with disabilities whose needs are not being met. Does NCOSS have a different view on that? Do you know of methods in use elsewhere that are more reliable?

Ms REGAN: It depends to what degree or to what level of detail we need to identify unmet need. For example, in the health system do we need to identify how many actual people are actually going to have actual heart attacks in the next two years? It is impossible to know. From an operation benchmarking viewpoint you can identify the number of people in any given population with those characteristics are likely to be at risk to certain degrees. In the same way we believe you can do that with disability. We do not know if we subscribe to the lack of data. The reason we do not subscribe to that is that we often hear from people seeking data and sometimes people within the department. We just do not have the figures.

There is so much data that is sent into the department every year by every service provider that is not analysed. It simply goes in and sits on a shelf and no-one does the analysis of that data. We have to know whether we are asking the right questions, but I am absolutely sure that mining that very important and very regulated information would give us much more information on the general directions in the general populations. That is why our first recommendation is about the Hon. John Della Bosca's benchmarking exercise. In his public report to the sector, which he did twice a year, he said that this was coming. But it did not ever come. We know that it was finished but we do not know to what degree. We certainly believe that there is enough information around to give real directions about how many people are likely to be required and what type of service, how long they are waiting, and at what stage in their lives.

The Hon. HELEN WESTWOOD: Another area that we heard evidence about this morning was the number of NGOs delivering services within the disability services network, and whether there is an optimum number and optimum size, whether we have duplication and waste because of the number of service providers within particular disability categories. Does NCOSS have a view on that? Do you believe there is an optimum number, an optimum size, for an NGO? We heard also of the concern amongst smaller NGOs of the growth or cannibalisation in the larger ones.

Ms REGAN: We talk about this a lot at the HACC issues forum and various other forums that we are involved with. We do not believe it is the size and the nature of the industry that is important here. We identify that the implementation of competition policy did absolutely expand the number of service providers. We have to be really clear about where that comes from. That is in both the disability services and HACC program. New South Wales has the most HACC service providers in Australia, more than twice as many as the next nearest State, which is not Victoria but Queensland.

We have a lot of service providers, and that is the nature of the beast. I do not know how it makes it worse; I think it just makes it different. We are strong proponents of self-directed and individualised funding for people with disabilities. We think this is the way of the future and it will provide solutions. We think it will produce efficiencies and we also think it will greatly improve consumer satisfaction in the use of disability services. If that were to come in, and we believe that is an evolutionary process, the industry would settle itself because the purchasers of the services would be the people who actually use them.

Right now there is a disconnect in the market when we use market theory. The people who are actually purchasing the service are not the people using it. So the satisfaction and degree of quality can be quite different, and the way that is measured can be quite different. When a person with a disability and their family become the purchaser suddenly the services we all know need to lift their game, but no-one is doing anything about it. They will lift their game or they will be out the back door. Those services that are providing creative, flexible or responsive services will be having people come to them with their packages saying, "We want a bit of what you provide". That is the way forward.

Right now NCOSS has a position on the industry which is that we believe in a vibrant and diverse industry. We believe that there should be small, medium and large providers, but not all large providers and not all small providers either for that matter. We believe that during the transition from one system to another, that industry needs to be protected, developed—as we do now, as we continue to do those things now. Also, we believe the success of self-directed funding will depend on a vibrant disability industry co-existing at the same time. Then we think that the self-directed will start to direct the types of services and the degree of services that will be received. Does that help?

The Hon. HELEN WESTWOOD: Yes.

CHAIR: Expanding on that, I assume that you obviously would have drilled down on the actual services that are provided. I have not heard of anyone disagreeing with the concept. However, the issues that arise when you are drilling down are the issues arising out of adequacy of service and those issues of choice. There is freedom of choice and freedom to choose, and subtle differences between the two cause great difficulty for the person making the choice because the choice they make may make them worse off. We have to ensure that they are making a choice that is to their advantage and does make them go backwards. I appreciate that people are entitled to make bad choices. You would have heard the previous evidence and submissions. If you are making a choice, for example, to become an employer in an environment where it is not a smart thing to do, we may be setting up those people to fail. I assume that when we think about the user making choices that we are drilling down into the bowels of possible outcomes.

Ms REGAN: We are. At the HACC Issues Forum when we talk about some of these issues mostly we are talking to providers. They are interested in going forward with this. It is not just others who are interested in going forward as well.

CHAIR: I was thinking more about the person using the service and making a choice.

Ms REGAN: I think you are absolutely right. But if you talk about what we have right now, a person with a disability has to fit into a very regimented set of boxes before they get the types of services they want.

CHAIR: I am saying let us make it as flexible as we possibly can and make the choices as varied and colourful as possible, but in doing so we do not set up the user to fail.

Ms REGAN: Yes.

CHAIR: In the sense that we give them a fluffy bright toy that comes back to bite them.

Ms REGAN: The experience of overseas is that people make very conservative choices in their first few rounds of funding—very, very conservative. It is only the few champions who decide to do the odd creative thing here and there, some of which succeed and some of which fail. But where those successes are clear they tend to infect others to take a few chances and do something more creative. The conservative choices are the ones that generally kick off, so there is a time to evolve. I also would like to share an analogy that happened in the HACC program. In the early 1990s the system of Community Options came in, which is a brokerage system in HACC.

CHAIR: Attendant care?

Ms REGAN: No, it is a brokerage system in HACC called Community Options.

The Hon. HELEN WESTWOOD: Where you could buy the services you need.

CHAIR: You would buy attendant care?

The Hon. HELEN WESTWOOD: Any sort of care, whatever you need.

Ms REGAN: For older people and people with disabilities in HACC, not in disability. At the time we were only three or four years into the development of the HACC program. So there was not one of each type of service in every area, as there almost is now. We, myself included, were very cynical that a brokerage system would work when there were not any services to purchase. The very smart and very clear learning from that was when there was money to purchase services there were services soon after that could be purchased and they developed naturally and evolved. We were saying that we did not think this was a good idea. We wrote papers on it at the time and we were wrong. It did develop around the availability of brokerage in the same way the experience overseas and in other States has been. People can make a few creative but fairly conservative choices and then build on those over time. Clearly, you do not choose nothing but you can develop over time. The other thing that quite often people react to when we talk about self-directed funding is that this is the system we have now and that tomorrow it is all going to be different. It simply is not; it is going to happen over years.

The Hon. TREVOR KHAN: You have talked about overseas experience. Are you able to provide in detail any examples of that overseas experience?

Ms REGAN: Hundreds.

The Hon. TREVOR KHAN: I do not think that is necessary.

The Hon. MARIE FICARRA: Send them to Trevor.

The Hon. TREVOR KHAN: You must have some examples?

Ms REGAN: I have been to the United Kingdom and I have gone to the experts. I now have a small resource library of good evidence that we use to support going forward. I am very happy to make them available to you.

The Hon. TREVOR KHAN: From my position that would be great. It seems to have the unanimous support of the Committee members, almost.

The Hon. GREG DONNELLY: In your opening statement you used the word "crisis". We have heard from a range of witnesses today. Putting aside for the moment that government witnesses would not use the word "crisis" to describe how they are doing things at the moment, witnesses from the Disability Council of New South Wales and National Disability Services have not use the word "crisis". What is behind your statement that things are in a state of crisis?

Ms REGAN: We would say there is a crisis looming and there is such a degree of unmet need at the moment that we hear some really tragic stories. At NCOSS we are not supposed to hear tragic stories. Our members are supposed to hear tragic stories. Yet people become so desperate that they see "Social Service" and they ring us and tell us.

The Hon. GREG DONNELLY: Do we have a looming crisis ahead if the funding and other structural matters do not change?

Ms REGAN: We would say that there is a crisis now in supported accommodation. Families are breaking down with people with disabilities. People are asking us how they can relinquish their beloved adult with disabilities because the family cannot continue to cope. People who live in nursing homes, young people with disabilities, are ringing me saying, "How can I get out?" We have the ludicrous situation of a family on the north coast who cannot get enough continence aids but is offered a holiday. The creative service provider has been providing their continence aids as part of the respite package, which is a little bit naughty. That has been found out and halted. Now this family has the absolutely ludicrous position of not being able to get enough continence aids but being told they should have a holiday. There are those kinds of things that happen day in and day out.

I am also an advocate in my non-paid hours. In my non-NCOSS non-paid hours I know of one woman who could not get equipment into her house in order to have her son, who had very high support needs, seated and into bed. This was only about three years ago. She used to put a sleeping bag on the floor and she fed him on the floor until her own shoulders gave out and she had to go into hospital. Only at that point was she offered supported accommodation for her son, when she had completely broken down. These stories just happen over and over. It is shameful. Because of compassion fatigue they do not all hit the newspapers. People are not prepared to put their private details in the public arena. We would say that it is an absolute crisis, and we believe it. There are many, many, many stories with that degree of need. There are an absolute number of people who are in crisis. You do not have to go far to find what those crises and those stories are.

CHAIR: Sadly, you are not suggesting that is a new thing?

Ms REGAN: You wanted me to explain how the crisis is and I was—

The Hon. GREG DONNELLY: We heard evidence this morning that a number of people do not interface at all with the government department, even if you take into account the non-government specialist service providers. They range into many thousands of people. I suppose a number of those people you could consider are in crisis.

Ms REGAN: But there are others whose needs are undermet. We have had two families in the past four years come to us to talk about how they can relinquish their adult. They are already connected with services but there are no supports. You can have a day program for your adult with disabilities, which they need, but the family is saying, "We cannot cope any longer. We need supported accommodation." But because they were not broken down they could not get in. They were not prepared to relinquish into a hospital or at a police station. That particular family ended up going to a hospital. This was a loving family. This was not a family that just wanted to drop off and walk away. This was someone who was appreciative of the day services but saying, "It is not enough. We cannot continue anymore." They wanted a proper placement. They did not want anywhere for their son. They wanted a proper placement that they could be comfortable with where the relationship could remain intact during that young person's life. The relationship completely broke down because of the way in which they had to receive services. That is not an unusual story, sadly. I do not know if I have—

The Hon. GREG DONNELLY: You have articulated the position from your point of view quite clearly and the individual cases. I accept on face value these cases that you have mentioned. I am still not quite clear—

Ms REGAN: The numbers that I gave earlier are pretty devastating—the 1,400 places that Strong Together will deliver when we need 10,000 places. You can imagine there is a degree of hardship there. There is also a degree of hardship amongst people who are now not connected to the system. I suppose the way I choose to illustrate those is with a few stories. Just last week I met an Aboriginal woman who works in human services whose daughter with disabilities and on the disability support pension receives no services whatever. This woman happened to mention to me that she is not receiving anything, she does not know where to go and she is at her wits end. How could this be? It is a crisis.

The Hon. GREG DONNELLY: In your view. I move onto this issue of the self-funding models, about which your articulation is that NCOSS is enamoured with and supports. Your testimony this afternoon is for an individual self-managed model for people with disabilities.

Ms REGAN: We believe that is the way to go, yes.

The Hon. GREG DONNELLY: Being the devil's advocate, is there any downside to that, shall we say, paradigm of managing people with disability that we should be aware of that perhaps lurks in the back somewhere? From overseas has it been seen there are issues associated with it?

Ms REGAN: We are not going to pretend that moving from what we have got to a new way to provide is not without difficulty. It absolutely is. In fact, NCOSS has a presentation we developed in April that also sets out the potential and real risks in going in and starting to initiate self-directed and self-supportive funding. We believe the benefits to people with disabilities far outweigh those risks and those risks can be managed. If you add it up, we would say that there is a degree of risk doing what we do now knowing we are not meeting the need in the way we most need to meet them. If we do more of what we do now we get the same outcomes, and we already know that people are not happy with those outcomes, we need to do something different that greatly improves and expands the degree and extent and quality of disability support services. We think this is one way to go forward with it.

We do believe, however, in a universal system, the universal system being that everyone gets a personal budget but, depending on their degree of need, not just any number, according to assessment. Some people we know at one end of the system will decide they do not want to make any decisions at all and will hand over their entire personal budget to an organisation. That has to be allowed and it has to be a legitimate decision for some of those people. We also know at the other end of the system there will be some people who will take the personal budget and as long as they fulfil their contracting, quality, data collection and occupational health and safety requirements, which they will have to do, they might say, "We will send all the paperwork in. We will do all the monitoring. Leave us alone, it will be cool." Then you will just put the monitoring in. Most people will, as in a bell curve, be in the middle. There will be a requirement for professional advice to find out what their person with disability or the person with disability needs to know, what kinds of things they should be considering in their own future, how to go about purchasing or acquiring those and also a financial intermediary where someone might purchase the back end. They might say, "I hand over to a financial intermediary to do my contracting, my recruitment, all my paperwork", just like we do with a tax agent. That will all be part of the package.

All of those things will be built in and available to the person and their family, depending on the degree of decision. It is a legitimate decision at one end not to do anything and to hand over the money. The reason that is a legitimate decision is that in a few years they might see that someone else is doing something more creative and then they will have the power to take back some or all of that package to do more creative things. We have found, as I said before, most people are very conservative for those first few rounds. They will choose what they already know until they get used to having the ability to make different choices.

The Hon. GREG DONNELLY: I am interested in taking this further in terms of this individual, personal, self-managed model. At the moment there are unlimited numbers of hours being contributed by family members to care for persons in the State with disabilities. Are there any implications if the dynamic is introduced whereby a financial payment or incentive of some description is paid to family members to care and, if so, what are the implications for the relationship between family members?

Ms REGAN: The experience we have of attendant care is that it can work very well and can expand the number of people who are available to provide the appropriate supports. However, under the new system that we are supporting, once a person is funded or employed they become an employee and then have the relationship of an employee.

The Hon. GREG DONNELLY: An employee of the person with a disability?

Ms REGAN: Yes.

The Hon. GREG DONNELLY: A Commonwealth contract employer-employee relationship?

Ms REGAN: It could be.

The Hon. GREG DONNELLY: What other employees are there?

Ms REGAN: I do not know.

Dr JOHN KAYE: Come on, Greg. You are the industrial relations man.

The Hon. GREG DONNELLY: It is a critical question.

CHAIR: With all the intended downsides.

The Hon. GREG DONNELLY: There is a whole range of consequences if we are talking about an employer-employee relationship, which I am sure you appreciate.

Ms REGAN: Yes, but if you have a financial intermediary they can be your employer. If you can take on the responsibility of being the employer and fulfil occupational health and safety requirements and provide all the industrial protections that are needed, you can do that yourself, as you can if you are a small business employer. We are not asking that people with disabilities be able to do more than anyone else can do. We are only asking that they be able to do the same as everyone else can do.

The Hon. GREG DONNELLY: What I was getting at was the commercialisation of the relationship, if I can use that word, between persons who are family members and the implications of that.

Ms REGAN: I think that would probably need to be managed but we are also not saying, "Here is your cash, off you go." We are building in safeguards. There would be some monitoring and there would be places to get advice and assistance in that relationship. Let us not pretend that does not happen now. We know of many families where the person with a disability pension becomes an integral part of that family's income, so the whole idea of the pension in the first place is lost in favour of the larger, more articulate and assertive group, which could be the family. We cannot expect a system to solve a problem that we cannot solve in any other way. We have to be careful that we are not attributing to the new system of purchasing or funding things that are not within the capability of a purchasing or funding delivery system to solve. That is human nature. We do not have to set people up against each other but the experience of attendant care is that that has not been a dreadful problem. That would be our closest experience.

There are some huge advantages too, so within culturally and linguistically diverse communities there might be a degree of ability to use personal resources in a way they never have before. The same applies to Aboriginal people. They might be trained to become carers within their own communities in ways that cannot or do not happen now. So it opens up some possibilities, but it does have to be done in a measured way. It cannot be a case of, "Here's your cash, off you go."

The Hon. MARIE FICARRA: In your submission you discuss the importance of independent information and advocacy for people with disabilities. Some of the submissions have been critical about ADHC and their funded advocacy services. How do you think carers can ensure they are getting independent information and advocacy?

Ms REGAN: We are involved in the Advocacy and Information Network in New South Wales where advocacy and information organisations meet to discuss issues of interest. As I have explained, there has been a review of that program for approximately a decade, which has been pretty exhausting for service providers and very uncertain. We are coming to the end of that, as I have described, but we have not yet seen the final papers. We believe that in future advocacy will be much more important. We believe the newer populations and generations of people with disabilities have different expectations from previous ones, thank goodness. We believe they want to have an ordinary life, a good life, just like anyone else. They will need people who can stand beside them who understand systems and how to navigate those systems. But those people should not be attached to a service provider. They should be independent so that they can make decisions in the best interest of a person unencumbered by other commitments as it were. The growth of individual advocacy in New South Wales has been problematic. We had hoped some years ago that with the review of the program we would be looking at tiers of advocacy, some at the systemic level—the type of advocacy that we do—but many at the individual level where individuals can have their problems solved. However, it should not be all one or the other; it needs to be hand in hand.

We do know we simply do not have enough people who can act for, advise or stand beside people with disabilities and their families. Surprisingly, it is not just the carers who need this. Very often it is adults with physical disabilities for whom the system is overwhelming, as it is for anybody, and they want to know how to navigate the system. For those people it is not just about how you get access to the disabilities specialist system it is how you create housing, how you negotiate with a landlord, how you get reasonable accommodation with an employer, how you talk to the electricity provider about a bill, how you navigate a mobile phone bill. All those kinds of things happen to people with disabilities and they need advocates as much as they need to be able to navigate the disabilities specialist system, and often more. That is the kind of thing we would like to see. As that evolves, hopefully people with disabilities will find their own voice. There will always be a number of people with disabilities for whom advocacy will be necessary. We would want there to be a critical mass of advocates who could act on a one-off basis here and there. They might have long-term involvement with a person but they will not be active in the long term. They will act on an issue, leave the matter, and then step back into it.

CHAIR: As we all do.

Ms REGAN: Exactly.

Dr JOHN KAYE: You made a statement, Ms Regan, that you felt the problem in predicting and understanding unmet demand and predicting where it will go and the need for services was not an absence of data. You suggested a large amount of data was provided to ADHC in the form of returns from various service organisations. Would you be able to provide, not necessarily now, an indication of what the data are, the quality of the data and the ways in which it could be used to validate the models that the department is using to understand and forecast unmet demand and for medium and long-term forecasts of the needs in the sector? This is an important point. A corollary of what you said is that ADHC is hiding behind the data issue when in fact you are saying that is not an excuse for failing to understand the unmet demand.

Ms REGAN: I will provide that information. We know that all funding services have to provide annual returns. There is a minimum data set that all funded services have to provide. It may not be complete and New South Wales still has a way to go to get an appropriate number of returns. However, this information goes to the department three or four times a year and then just gets transferred to the Commonwealth to some degree. There are annual returns, annual reports, performance reports and monitoring reports and it all sits on shelves. No-one is doing any analysis of how that can be used to identify degrees of unmet need and service level usage and then predict what is going to happen in the future. At every point we know the age and condition of the person from all that information. We do not know about the persons not using the services, but once you add that to population benchmarking you can use a few predictors. We would be getting quite broad information, not specific information that DADHC quite rightly say they do not have, but we think there is enough information to go forward and start to develop and improve the quality of that information.

Dr JOHN KAYE: I refer to Mr Donnelly's questioning of you about an existing crisis and a looming crisis. Can I get your response to the proposition that there has been a substantial increase in the funding of disability services in New South Wales but the rate of increased demand for those services has persistently outstripped the rate of increase of funding? So, from a public policy point of view the State is struggling to keep up and is failing to do so in many cases.

Ms REGAN: There is one service type where that has not happened and that is community participation and transition to work. Both of those are for identified school leavers with disabilities who leave school. The way in which that system works—I am not going to use the word "entitlement"—is that if you leave school with a disability you can receive a place in community participation or transition to work depending on your assessed capacities and your intentions. Transition to work for school leavers is a program under which once you are assessed you might have an employment outcome within two years. Those people for whom an employment outcome is not in their immediate or near future can go for community participation, which is dignified, daytime developmental activity for adults with disabilities. If they have not identified enough places extra places will be created. That is the kind of support we aspire to for the various different services that are required.

Dr JOHN KAYE: That support is not budget limited; it is demand driven. I am sure if Eric Roozendaal were here he would have some very harsh words for me for saying this. You are saying that because there is a human rights issue associated here we should not be budget limited in the way we provide these services; they should be provided to meet the need and the budget should follow.

Ms REGAN: Absolutely. Also, there is a common myth perpetrated that disability is a black hole and no amount of money will ever be enough to provide appropriate support for people with disabilities so why try? We say that because we have not had a deliberate investment for many years in disability services we have a way to go, but we believe it is not a black hole. Investing in people with disabilities will provide enough support, remembering that people with disabilities are also a resource and an asset of this country. We are losing quite a lot of human resources in not allowing people to extend their opportunities and try out their capacities. We are also not talking about all people with intellectual disabilities. There is an assumption that they are not contributors. We believe they are contributors. We are talking about people with brain injuries and people with physical and intellectual disabilities who can be contributors to the local community.

Dr JOHN KAYE: Of course, the value of someone to society is not necessarily their contribution.

Ms REGAN: Not their tax contribution perhaps, but in lots of ways.

Dr JOHN KAYE: Earlier today the Committee received evidence from the Disability Services network that funding needed to increase, on its figures, by $2.5 billion over the next five years, by which it meant the annual budget should increase by $500 million a year. That evidence was put on the record deliberately. Does NCOSS agree with that figure as a benchmark as to where we should be headed?

Ms REGAN: Was that the Disability Council that gave that figure?

Dr JOHN KAYE: National Disability Services.

Ms REGAN: We have not seen any of the costings for that and we have not done our costings. What we have done is mostly immediate costings. Our pre-budget submission sets out what we think the next year's State budget should spend pragmatically but we have not done overall costings.

Dr JOHN KAYE: I want to ask about Aboriginal community care and briefly about competitive tendering. The Committee has heard quite a bit of evidence that competitive tendering has an adverse consequence for many, particularly the smaller organisations that get outbid in their provision because they do not have the same capacity to develop a fancy submission. The Committee also heard that it creates uncertainty within an organisation. Not knowing that they are going to have certainty means that they cannot invest infrastructure and personnel and so on. Is that the view of NCOSS?

Ms REGAN: Yes.

Dr JOHN KAYE: You may take this question on notice. I refer to your recommendation to set a proportion of funding in each of the ADHC regions which is earmarked for Aboriginal service provision. I accept your evidence that there is a substantial problem for Aboriginal older people with disabilities, carers and families within their communities in terms of their vast unmet need. I think that is commonly accepted. Are you concerned that a set proportion of funding growth allocated within each region to Aboriginal service provision will produce anomalies across regions? How do you see this working?

Ms REGAN: At this stage it is just a recommendation. The New South Wales Aboriginal Community Care Gathering is a group of Aboriginal people who are interested in policy and progressing the needs, rights and interests of Aboriginal people in New South Wales. NCOSS provides the secretariat and has permission to include their evidence as part of our evidence, but we would be very happy to make members of the committee available to you if you want to speak directly to them at some stage. Basically what they say to us is right now we all know that we need to do better for Aboriginal people. We also know that the number of Aboriginal people using residential services is far below that of mainstream services. We also know that the number of Aboriginal people using package or in-home care is much higher than the per capita proportion in the mainstream community.

However, we also know that Aboriginal people experiencing moderate to severe disability 2.4 times the rate of the mainstream community. So even on a proportional benchmark basis we are nowhere near the degree of supports that we need for the Aboriginal community. What they say to us is in every single initiative or program Aboriginal services are always mentioned. It is always mentioned as, "We will get the mainstream services right and we will get to Aboriginal services after". The experience of the gathering tells me that often we run out of time or we run out of resources before we get to Aboriginal service provision. One region in ADHC has decided under the HACC program to circumvent exactly that happening and for about the past 15 years have identified a proportion of funding that comes off the top before anyone else receives funding that goes towards Aboriginal services.

The Hon. TREVOR KHAN: Which region is that?

Ms REGAN:: New England.

Ms REGAN:: As a consequence of that Aboriginal services are much better resourced than most other areas.

Dr JOHN KAYE: It is working and producing positive outcomes.

Ms REGAN:: So what we would say is, "Let us try this because what we are doing now does not seem to be working". So again it is the idea of trying something new, and, of course, it will depend on the degree of need and the proportion that is put aside and a whole pile of other variables. But we know right now that doing nothing is just not improving it in the way that we need to catch up.

CHAIR: I thank NCOSS for its ongoing important contribution to this area.

(The witness withdrew)

(The Committee adjourned at 5.21 p.m.)