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REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON SOCIAL ISSUES

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

At Sydney on Friday 3 September 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. H. M. Westwood

CHAIR: Welcome to the third public hearing of the Standing Committee on Social Issues into services provided or funded by Ageing, Disability and Home Care. Today we will be hearing from the Paraplegic and Quadriplegic Association of New South Wales, the New South Wales Home Modification and Maintenance Services State council, the Physical Disability Council of New South Wales, the New South Wales Council on Ageing People with Disability, the Futures Alliance and the Disability Trust. The Committee has previously resolved to authorise the media to broadcast sound and video excerpts of its public proceedings. Copies of guidelines governing the broadcast of 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. Witnesses, members and their staff are advised that any messages should be delivered through the attendants or the Committee clerks. I also advise that under the standing orders of the Legislative Council, any documents presented to the Committee that have not yet been 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.

MAX BOSOTTI, Chief Executive Officer, ParaQuad New South Wales, and

TONINA LOUISE HARVEY, General Manager, Community Services, ParaQuad New South Wales, sworn and examined:

CHAIR: 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 may subsequently publish evidence if they decide that it is in the public interest to do so. Would you like to make opening comments to the Committee before we go to questions?

Mr BOSOTTI: Yes, I would. Thank you very much for providing us with the opportunity to appear before the Committee. ParaQuad is a not-for-profit organisation formed in 1961. In fact, next March will be our fiftieth anniversary. For most of those 50 years we have provided vital care, support and clinical services to people with a spinal cord injury, their families and carers. We currently have a membership of over 1,700 people with a spinal cord injury across New South Wales, and we have assisted with the provision of these services to the community through, firstly, transitional and respite and permanent accommodation, specialist spinal nurses, occupational therapists and social workers to support individuals and families, a home-based personal care program currently servicing over 80 individuals across New South Wales, education and training programs for people with spinal cord injury and specialist services who are providers of care, community, and corporate awareness training on the provision of accessible services and programs.

ParaQuad currently receives funding from ADHC for, firstly, residential services at Ferguson Lodge of $2.6 million under Stronger Together, which, when augmented with part-pension contributions from residents, enables ParaQuad to operate a 40-bed facility at Lidcombe, a unique facility in New South Wales catering for the needs of people with a spinal cord injury, both permanent and respite accommodation. This facility is currently undergoing a major redevelopment due to a significant contribution by ADHC of $5.5 million, which was generally supported by a $5 million contribution by the Motor Accidents Authority towards the capital redevelopment of this facility, which has scope to provide care for 40 people with a spinal cord injury in a village environment. We also receive a contribution to supervise and support a transitional housing program in Sydney and Newcastle, where we have five studio units, five two- and three-bedroom homes and one three-bedroom unit. We have a funding contribution for information, support and advocacy in the Hunter region. We have a contribution also to support a clinical case management service within the primary health care team.

ParaQuad is most appreciative of the financial support it receives from ADHC in assisting in servicing the needs of the spinal cord injured community. However, historically ParaQuad has bridged this gap in the provision of services to the community and it has done so by operating commercial activities to address the shortfall in funds and by various fundraising programs. Some difficult times have been experienced over the years and it has become clear that commercial success is essential if service levels are to be maintained. Our submission deals with most of the key issues we face and essentially they are the need for: a greater degree of real data collection on the number of people with spinal cord injury—where they are located, the age groups—to provide a sound basis for planning services; an increased level of supported accommodation; a greater number of attendant care packages so people can remain at home; improved funding to increase the opportunity for the provision of equipment; and that there are gaps widening due to the implementation of a compensable scheme for motor accidents.

We recognise that ADHC has limitations in the funding it has to distribute and hence why Stronger Together two and increased funding is essential. People with a disability are living longer. Our effective medical care is ensuring that, and that will continue and, therefore, commensurate with this excellent result there is a need to adequately fund the service delivery on which so many people depend.

CHAIR: Thank you for your extremely helpful and comprehensive submission.

The Hon. GREG DONNELLY: Thank you for providing the Committee the opportunity to ask additional questions to your very good submission. The secretariat has developed questions to help the Committee probe deeper into your submission. In your submission you referred to a survey that was conducted by ParaQuad in 2009 which identified a major concern in the spinal cord injury community around supported accommodation. Many other submissions have also identified that issue, for example, the Northcott Disability Services that has already given evidence to the Committee. That service stated that unless one is homeless one will not get accommodation because of limited resources available. Will you share your thoughts about the impact of the shortage of supported accommodation and its impact on people spinal cord injury and their carers? What improvements are required to progress supported accommodation from being crisis driven, urgency driven through to a more well-planned arrangement?

Mr BOSOTTI: I think we would probably both like to answer that question, but let me go first. The survey that we conducted showed that a large proportion of our membership who were concerned about supported accommodation, particularly as they were with carers who were ageing, and were wondering where they were going to end up when their carers were no longer able to care for them. In fact, as an aside, one of the key motivations for my coming into this sector was the fact that I read quite a number of letters in 2004 and 2005 that were submitted to then Ministers from many people and they all read much the same. The 87-year-old mother and her 89-year-old husband were concerned about their son Alfred who was 49. The mother said she could no longer look after her son. That is a situation that we are continually finding. People are living longer, as I said in my opening remarks, and the question is where do they go if there is not sufficient supported accommodation?

Ferguson Lodge is unique in New South Wales in that it specifically provides for people with a spinal cord injury for that supported accommodation but the alternatives to that are basically to go into aged care facilities. The same applies with young people as well; if there are no places for them to go in specialised accommodation then certainly they end up in aged care facilities, which is totally inappropriate.

Ms HARVEY: Because of the changes in modes of accommodation over the last decade especially, there is a differing focus on where people may end up in the long term. We have a lot of people who come to our service for respite care from the rural country areas but do not have a desire to find alternative accommodation in Sydney because they want to stay linked to their communities and their family, which we can well understand. There is some discordant now because of policy directions around where people live. Compensable injuries can have accommodation which is affordable, and they can link into quite well, and it is funded and supported. We have people who may have got compensation 20 or 30 years ago and have used it appropriately, but their lifespan has now extended so their compensation is running out and, therefore, they have nowhere to go.

There is also a lack of supported accommodation for people who are ventilator-dependant. Certainly that is an issue that we are trying to address in our current facility. At the moment the only place a person who is ventilator-dependant can go for care is in an intensive care unit in an acute hospital. If the family requires respite that is their only alternative, and as you know, the shortages of intensive care beds are quite high. The impact on the families is profound. Ageing carers are one, but also sibling carers and younger carers, so if people do not have somewhere to go for ongoing accommodation and care then the stress comes back to the family. We see a lot of that throughout our psychosocial services in terms of providing support to families to manage and cope with people in their own homes and environment. We are currently doing some work in the Newcastle region with another gentleman who has a daughter, who is in her forties now, who has suffered a stroke—it is an organisation called the Right Care Inc—and scoping around the accommodation needs in the Hunter regional area. We feel that there are possibly not the numbers to look at another large spinal conglomerate of accommodation services in rural regions, but there is certainly opportunity for us to partner with other organisations who are looking after people with physical disability where we may be able to support programs around supported accommodation in the future. But again it is not getting funding for capital works—we can generally raise those funds—it is the recurrent funding, which is always an ongoing issue for us, and that is where we are having some difficulty now even with Ferguson Lodge.

Mr BOSOTTI: As far as I am concerned, probably the most key element in the whole submission really is the issue of supported accommodation. I think the first issue is a fundamental commercial one in terms of where are the people located and what are the numbers we are planning for. We at ParaQuad have endeavoured—and I personally have written to Flinders University to try to break the privacy issue in terms of telling me, just by postcode, how many people there are with a spinal cord injury. We know in Australia there are somewhere between 9,000 and 10,000 people with a spinal cord injury. There is a spinal cord injury almost every day and that number has been consistent for the last 20 years or so. Our membership, as I have said, is just over 1,700. There is another organisation in New South Wales that has several hundred members. If you start looking at a reasonable geographical distribution of those people across Australia you would have to say that in New South Wales there is quite a lot more than those members that we have on our books, so the question is where are they and how can we plan effectively. One of the things that I find very frustrating is unlocking the keys to providing that sort of unclassified data just for planning purposes, so that we can say there is a pocket of people in the Hunter area or up in Coffs Harbour or further north and we can start to look at planning for the kind of facilities of supported accommodation that will suit.

The Hon. GREG DONNELLY: Without interrupting your train of thought, in relation to the issue of trying to obtain good clean data about location, could you explain the hurdles that you have experienced in terms of being able to obtain that information?

Mr BOSOTTI: The experience is that we just cannot get that data for a number of reasons. First, if you look at the way records were kept in various spinal units, they only go back so far, so we are probably talking about the need to go much further back. As Tonina indicated, there are people who have had injuries for 30 or 40 years. They are living longer. We need to know who and where they are and the current record system does not have that, but there are some statistics which are kept at Flinders University which may be useful—using the 80-20 rule, I do not need to know exactly, but just approximately where are these people. The other thing is that we are also finding that, as with able-bodied people, we are having movements of people from other States. The tendency with a person with spinal cord injury is that, because their thermostats are different from ours, they prefer to move to a more temperate climate, so we are seeing growth from the Hunter region north. They are people from New South Wales, but also from interstate, so there is a movement of people that we need to cater for.

The difficulty with supported accommodation is the fact that, while there might be some capital funding that is available through Ageing, Disability and Home Care [ADHC] or some private sources in terms of raising through donations, the real hub of the issue is recurrent funding. This is the issue that Ageing, Disability and Home Care unfortunately has in terms of its budget and being able to commit to a recurrent funding program. We have our own recurrent funding issue that we are discussing at the moment for the new facility, but this seems to be the real blocker. For example, if we had determined that there was an opportunity to provide some supported accommodation in the Hunter region, let us say it is a residential house with maybe three or four bedrooms and a sleepover, and we were able to raise the capital cost to construct that facility, the issue is where are the funds coming from to operate it in terms of recurrent funding, because the care packages that are required are expensive.

Here again there is a little bit of inflexibility in terms of the attendant care packages, as scarce as they are—and there needs to be more—but let us assume that we were fortunate enough to have a facility built in the Hunter region, as an example. It would be economically the best outcome if we had an attendant care package, if you like, designated to the facility—in other words, provide care at the facility and have more bang for dollar, if I can use that expression, to cater for a number of people rather than having an attendant care package assigned to an individual. That is also a discussion that we are having to try to break that nexus, saying let us be more flexible with the package and can we do more with that amount of money. Rather than going to an individual, spread that amongst a number of individuals. I can sit here today and say that I know anecdotally there is a tsunami running at us—I do not know the size of it, but I would love to. I also question whether the various departments know what they are doing down the track because, if they do not have the figures, how can we plan appropriately?

Ms HARVEY: Also on the question of data there seems to be a general funnel called "Disability" and whilst our interest is in spinal cord injury I know it is difficult to get data in other disability types as well because Centrelink, for instance—

The Hon. GREG DONNELLY: It is not disaggregated?

Ms HARVEY: It is not disaggregated at all, so there is no way of really looking at what the numbers are.

The Hon. HELEN WESTWOOD: Could you elaborate on the difference between metropolitan and regional New South Wales in terms of accommodation services and other support services that your client group is in need of?

Ms HARVEY: All the spinal services are metro-centric. All the acute spinal units are based in Royal North Shore and Prince of Wales. There is also the Hunter spinal team, but that is it. So anyone who lives outside the boundaries of those regions has limited access to specialist services. Our organisation provides a state-wide service, so we offer consultancy advice and support to people in rural and regional areas. We work also with the State's spinal services in doing some rural outreach and have recently just been to Tamworth and Ballina and are about to go to Dubbo to run some rural information clinics. What we see when we go to those clinics is that there is stress for people with spinal cord injury and general disability again around accommodation. Recently I think in the Far West a hospital was closed. I cannot remember where it was.

The Hon. HELEN WESTWOOD: Gulgong.

Ms HARVEY: And a gentleman was going to be moved to another hospital, away from his family and community. That is not atypical; it happens all the time. People lose the right to age in place, so if they are at home and they want to age at home and die at home, they do not have that opportunity. In specialist accommodation services they get to a certain age and then they are deemed to be appropriate for aged care. For people with spinal cord injury, that is often an absolute nightmare. Aged care services do not have spinal expertise. It takes particular knowledge to manage people, especially with high level quadriplegia. It is different from nursing home care. We often offer some specialist consultancy and training to nursing homes that have spinal clients for that purpose.

Families feel disengaged from one another when people are transferred away from the community and often that limits their ongoing family involvement. We have one resident at Ferguson Lodge at the moment who came from a rural area who is eternally frustrated because he would rather be on the farm. He does not really want to be in Sydney, but he has no choice at this point in time for his care. So there are a lot of issues for families around sustaining and maintaining those strong links. As we age we are at our most vulnerable, it is a time when we need the consolidation of support from our family, and that certainly is not often the case for people in rural and regional areas.

The Hon. HELEN WESTWOOD: In relation to the case you just referred to, does that mean some families are separated because of a person's spinal cord injuries?

Ms HARVEY: Absolutely. Sometimes people can be separated for long periods of time. Pressure area management is a huge thing for people with spinal cord injury. They get quite severe pressure sores and often that requires long-term bed rest. Sometimes it requires medical intervention or conservative care. Places in the rural environment do not always have the beds available for long-term full bed rest care. Often we have people come down to Ferguson Lodge for that period of time. That can go for six to twelve months and often longer, which means people are away from their families, their communities and the normal activities of daily living for that period of time. That is a significant impact on the family.

Dr JOHN KAYE: Are you saying that is for the period while their bed sores, pressure sores, are recovering?

Ms HARVEY: Yes.

Dr JOHN KAYE: It takes that long?

Ms HARVEY: Yes. It depends on the size of the sore and often people have multiple episodes and with multiple episodes you get limited healing, so they require skin grafts.

The Hon. HELEN WESTWOOD: Are there accommodation options so that families can stay together in Sydney?

Ms HARVEY: At the moment, no. What we are trying to do with Ferguson Lodge is to provide the capacity, especially in the units, for families to be able to come and stay if they choose to do so. Often families have children in school and they have other commitments and work commitments. We are not talking about people from high socioeconomic areas. Often they do not have the funds to be able to give them the luxury of leaving home to come down and be with their family members. So, it is often more complex.

Dr JOHN KAYE: In your submission you talk about the issue of case management. You suggest on page 5 that case management is only really required for people with intellectual disabilities, not with physical disabilities. We also had evidence from Spinal Cord Injuries Australia suggesting that case management is a very useful go-between in the provision of services, so regardless of people's intellectual capacity there was often a useful role for case management. Could you expand on that?

Ms HARVEY: That was not the intent in the submission. The point was made in relation to getting people into accommodation services. There is an ADHC policy that requires people who want to go into residential care to have a case manager to be able to make that process work. Our experience working with the ADHC office around that is that some of our clients do not wish to take up the option of a case manager. They feel they have the capacity to manage their own affairs and are quite capable of coordinating their own pathway. While we can give them some social work support to do that it is not deemed a case manager role. That has not been accepted as part of the pathway that ADHC would like to see things done. There has been some discordance around the application of that policy for people with spinal cord injury. In regard to case management per se, some people may elect to have a case manager and if they choose to do that we would support them.

Dr JOHN KAYE: Are you suggesting the way to optimise individual autonomy is to allow the individual to make a decision as to whether they want a case manager or not?

Ms HARVEY: For people with spinal cord injury with cognitive ability I cannot see a reason why that would not be the case.

Dr JOHN KAYE: The issue of individual funding has been talked about in this Committee quite extensively. Do you think individual funding would result in a redistribution of case managers to people who have a greater need for those case managers?

Ms HARVEY: Are you alluding to individual case funding in relation to attendant care?

Dr JOHN KAYE: Yes, I think that is correct.

CHAIR: Let us deal with that anyway. There may be other issues.

Dr JOHN KAYE: The Committee has heard evidence in relation to attendant care and other issues where funding is being individualised.

Ms HARVEY: Basically the philosophy and policy of ADHC is that people have individual choice in relation to the use of their funding packages, so therefore they can choose their provider or they can choose to be individually funded to coordinate their own care. As far as I am aware, there are not a large number of people who are doing individual funding at this time so it is probably a little premature to say how that could work. The people that I know of with spinal cord injury that were involved in the initial pilot for individualised funding certainly have the capacity to be able to manage their own affairs because they had their own businesses and were used to coordinating those sorts of business arrangements. I am not sure whether individualised funding would enhance the opportunity for case management. I am not sure of that link. I could not really comment on that.

CHAIR: Taking the issue possibly a step further, in regard to autonomy, choice, flexibility and control by the individual, which is the ultimate aim of all of us, as much as we can possibly do it, I understand from one very articulate submission that there are some difficulties in having a mix of, say, State-funded home care and federally funded attendant care. They appeared to be being told that, "You can be an individual but you can only be federally funded with attendant care as long as you give away home care funded by ADHC." Can you indicate what that is all about?

Ms HARVEY: I assume those are the Federal funds that come to ADHC through the State Government and get packaged into attendant care packages. Certainly ADHC has historically run its home care program. The home care program also has a high needs pool associated with it for people with high level disability. Once you receive an attendant care package you are then disengaged from the home care services, so the funding streams are separated by ADHC.

CHAIR: This person appeared to be saying that they were extremely happy with their home care services, as far as they went, but they also wanted to add some attendant care to give them added flexibility in certain areas that would have enabled them to take control of their life in a much more advantageous way to them and they were stymied by the fact there was this bureaucratic problem.

Ms HARVEY: It is the rules that ADHC runs both programs by that cause the discordance between the two.

CHAIR: Do you have any recommendations or ideas you can give us today or tomorrow about overcoming that difficulty?

Ms HARVEY: There seems to be a lot of discordance between all the different types of care packages and from my perspective we really need some central point through which people apply for care and for that then to be streamed through, rather than people saying there is this package or that package and if you fit this set of rules you go here and if you fit that set of rules you go there. What needs to happen—I think I put it in the submission—is a no-wrong-door policy: there is a single door which people can go through and their needs are assessed and identified and a care package is developed according to those needs.

CHAIR: Which is a very different thing from one size fits all.

Ms HARVEY: Yes, absolutely.

CHAIR: There is one door but we are not talking about one size fits all. You are talking about the complete opposite.

Ms HARVEY: Absolutely.

CHAIR: I think you have some large residential centres. The Committee has heard evidence that ADHC initially stated it would close large residential centres. ADHC has more recently communicated that it will be redeveloping these centres instead. At last week's hearing the Council for Intellectual Disability stated that there is "an international trend to move from congregate settings for people with a disability to smaller more individual settings". Could you advise us of your organisation's view on the use of large residential centres to accommodate people with disability? Are you able to identify the models that will result from redeveloped and large residential centres?

Mr BOSOTTI: When you said earlier in your comments about one size fits all, that is the nub of the issue. It is quite clear from our experience that there is a variety of accommodation models that will suit. Certainly we have a facility that can cater for up to 40 people. Some of the residents of that facility have lived in group homes and prefer to live in a congregate facility. There is a range of options that we are looking at.

Obviously, if people can stay in their own homes, that would be fantastic. Some choose not to. It is the same with group homes and the same with congregate facilities. There are a number of models that will suit quite a range of individuals. It is that choice which is one of the main things that our organisation tries to provide to our membership and the wider community. That is what it is all about. I do not think there is any specific answer to your question in terms of what is the right model. I think that there are a number of models that need to be deployed to give people those different choices.

Ms HARVEY: It is also not just about the buildings but about how services are operated and individual choice that people retain as part of their involvement in that service. In the redevelopment of the current facility we have a large high needs area, but they are single rooms with en suites in two wings, and there are 12 beds in each wing. In each of the units, there are two-bedroom units that are also on the campus. It is not an all-in-one facility.

The model of care is really about where institutionalisation can determine how people's lives will progress. What we need to ensure is that there are good programs around social inclusion and community participation which are streamed through any model of service delivery, regardless of the setting. One of the battles that we have had with ADHC in terms of enhancement of our funding is getting funding to support community participation. Certainly we have raised external funds to try to sustain programs so that residents will be able to go out and participate in the community.

Having said that, most of our residents are out most days, except for a couple who are now in their eighties and who choose not to. But most of our residents use public transport. They get on an accessible bus and they come to town. Yesterday I had a conversation with a gentleman who told me he had been to Flemington markets on Sunday to buy some bits and pieces. It is about the way that they are supported to engage with the local community.

Mr BOSOTTI: That is one of the big points about the redevelopment of Ferguson Lodge. It is at the old Lidcombe hospital site and it is surrounded by the TAFE university. The rest of the site is being developed by Australand into a residential facility so that in fact the community is coming to Ferguson Lodge. The residents of Ferguson Lodge feel that they will well and truly be integrated into the community. They have access to public transport, good facilities, and they are free to come and go. Tonina has raised an important point: It is not just about the building, but the integrated care that goes along with it.

The Hon. HELEN WESTWOOD: Is there any chance of those Australand homes being purchased to look at family accommodation for your clients who are in Ferguson Lodge?

Mr BOSOTTI: Most of them are two-level homes.

Ms HARVEY: They are not accessible.

Mr BOSOTTI: It is a commercial enterprise. I guess the economics dictate that the style of the accommodation is quite different.

The Hon. HELEN WESTWOOD: It was never conceived as part of that plan to have some accommodation that is accessible?

Mr BOSOTTI: Not that I am aware of.

Ms HARVEY: No.

The Hon. MARIE FICARRA: Thank you for coming in. Your submission states that there is a lack of partnership between New South Wales Health regarding the provision of therapy services and equipment services. Could you give us a little bit more information on what you mean by that?

Ms HARVEY: I worked for 34 years in the health sector prior to coming to work in the disability sector, and I have been in the disability sector now for five years. When I came from the health sector, I was astounded at the lack of acknowledgement of the existence of the disability sector and the health care needs within the disability sector.

I sit on the EnableNSW Advisory Council and on the State spinal cord injury clinical development committee as a way of having some linkages into New South Wales Health and the programs offered by New South Wales Health. Currently at Ferguson Lodge, as I mentioned earlier, we have pressure area management for people with spinal cord injury. We admit people for what we call conservative treatment, which means it is non-invasive medical care for management of pressure wounds. What we can do there is look after somebody in that setting until they are healed enough or well enough to go and have surgery, and then they can come back to us for post-operative healing and seating protocols. It is generally about three to six months before somebody can again sit in a wheelchair after surgery for a pressure area. We can do that, and we do that in some cases.

We have been trying to liaise with New South Wales Health to gain some funding to provide that care. But New South Wales Health cannot see any benefits to them in providing funding to us to do that care because it does not free up a hospital bed for them, even though they would have somebody in hospital bed had we not taken that person on board. There is a lack of recognition around the opportunities to work together. What we actually are doing is saving approximately 38 bed days per person in an acute hospital bed, but because New South Wales Health has always got somebody to fill that bed, there is no cost benefit that is visible to them.

The Hon. MARIE FICARRA: Will you be limited eventually in how much of the support services you can provide?

Ms HARVEY: We will be on an ongoing basis, but to me it is certainly just a waste of resources to put somebody in an acute hospital bed from four to six months when we can care for them for probably for four and a half months of that time. Then they might only need to be in an acute hospital bed for two weeks. To me there is a good opportunity to reduce drain on acute hospital resources. It is actually a lot cheaper for the Government's purse for us to look after them in our facility, rather than putting them into an acute hospital bed.

The Hon. MARIE FICARRA: Absolutely. It makes sense.

Ms HARVEY: Certainly the quality of life outcomes are greater because they are in an environment in which they are integrated into a community setting and they are much happier, and they heal better.

The Hon. MARIE FICARRA: Your submission also states that home care does not provide services to people if they are considered to be too high in their needs and that may in fact leave them with nothing. Could you give us a little more background into the services that the high needs clients can access and any changes that you feel may be required in the eligibility of this home care program?

Ms HARVEY: I am speaking anecdotally from experience rather than what I know to be true of home care, so please take it in that context. My understanding is that when somebody applies for high needs pool, if there is funding available they are prioritised. The level of priority determines when they get their package. I think I gave an example in the submission about it taking 12 months to get somebody funded into high needs while they were still on the waiting list for an attendant care package. The alternatives are that there is no care or the family provides care.

There does not seem to be a baseline in this sense: If somebody requires care, what is the baseline of care that we can provide until such time as there is additional funding to provide the full length of care? There seems to be no negotiation with the client or the person and their family about what the care needs are, or what is going to happen if they do not get the care. What happens to them in the interim is out there in the ether. There does not seem to be any sort of coordination.

The Hon. MARIE FICARRA: Again, going to your submission, the section on attendant care, you identified issues such as long waiting periods and a lack of equal opportunity to gain access to these services. Could you tell us more about how you identify how long people generally wait to receive services through this program?

Ms HARVEY: Attendant care people can wait for long periods of time—we have one gentleman who waited three years. There seems to be a low priority of people depending on age, because different care packages cut in at different times. If you have your injury at the age of 50 and beyond, your ability to get care packages under the attendant care program is pretty limited. If somebody has not got a package by the time they are 55, you can pretty well guarantee they are not going to get one. We get told that they need ADHC assessment, they will soon be suitable for an aged care package, but aged care packages certainly do not have the amount of hours of care for people with a spinal cord injury. You are looking at a general minimum of 35 hours per week that people would need with a spinal cord injury.

The Hon. MARIE FICARRA: So what is the answer? Increased funding is obvious.

Ms HARVEY: The answer, again, is taking down the barriers between the criteria required for various packages and really having a look at what people's needs are, assessing those needs and having a base line of care and then building on that.

The Hon. MARIE FICARRA: In reading the submission I got an impression you thought there might be a lack of equal opportunity to access.

Ms HARVEY: Yes.

The Hon. MARIE FICARRA: So what you are proposing is to make it on a more equitable basis?

Ms HARVEY: Absolutely.

The Hon. MARIE FICARRA: Individualised, sensible, evidence based?

Ms HARVEY: Yes.

The Hon. MARIE FICARRA: Also, can you give us a bit more information about the ventilator dependent client that you described in your submission who funds his own services. His money is running out. He may now be left with the only option of presenting to a hospital.

Ms HARVEY: Absolutely. This is a gentleman who sustained his injury many years ago. His compensation package was, I think, about $1.5 million 20 something years ago, which is certainly a great deal less than people get awarded now. His life span is obviously greater. His money has been managed by the Office of the Guardian, so it has been well managed, but his funds are running out. There is no funding available for the home ventilation program currently for him to get funding for his care. So once his care package—he has nowhere to go other than to an intensive care unit.

The Hon. MARIE FICARRA: You mentioned before when you were talking about supported accommodation that you have a lot of ventilator dependent clients who need intensive care. Can you describe their quality of life?

Ms HARVEY: It is pretty awful. The incidence of ventilation dependence in quadriplegia has decreased over the years, due to new technology, air bags for instance in cars. People are not getting such high level injuries—but having said that there were three incidences of ventilator dependence quadriplegia last year, I think over the last Christmas period. I know of cases where people who are ventilator dependent have been in hospital for up to three years prior to getting home. There is nowhere in the community currently for people to go for respite, as I mentioned earlier. Within the rebuilding of Ferguson Lodge, we have liaised with EnableNSW and the State's spinal services, recognising this problem, to make sure that two of the units have been outfitted with enough circulation space and enough power for people who are ventilator dependent, so we can accommodate people who have those needs. The sticking point is, again, the guidelines around what people get funded for and when. Under the home ventilation program people will only get funding for their equipment six weeks prior to their discharge from a hospital. If they came from a hospital to our services, they would still be classified as "in hospital". Therefore, they will not be funded for their equipment. So we cannot even offer a transition program at this stage.

There is the added issue of who pays for care. People who are ventilator dependent require 26 hours of care, which gives a two hour hand-over. Therefore, we are not funded to provide that care currently, so we would require somebody to bring their own package of care with them, so that they have their own carers trained. Then it is: Who trains the carers? Who takes responsibility for that? There are a lot of issues. Again, the need for partnership between Disability and Health comes to the fore.

The Hon. MARIE FICARRA: The terms of reference require us to look really into the historical and the current level of funding in relation to any unmet need. Within your sector, are you able to comment on levels of funding and how they relate to your unmet need? Of course, you mentioned before that you do not know the precise extent or the demographics of what is out there for the future, but in terms of us making recommendations, have you got anything that you want to tell us now that you would like us to include?

Mr BOSOTTI: I think the important point was the gathering of better data to determine that unmet need and everything flows from that. Quite clearly, both from the supported accommodation side to attendant care packages, I think one can better determine that when we have a better picture of exactly what that sector looks like.

Ms HARVEY: The other thing to think about is that historical funding is based on historical policy. Therefore, as policy changes there appears not to be an enhancement of funding to support the policy changes that are being required. The ethos and the philosophy of care around disability has significantly changed in the last ten years. Certainly, disability standards have engaged the sectors to enhance quality of life for people with a disability and there has not been the enhancement of funding in line with those changes. The independent choice around provision of services and care, community participation, social inclusion, the funding that supports that activity for individuals is not there, certainly for people who have been living with a disability for more than ten years.

CHAIR: Could you elucidate on why you think that is the case, because on face value one would expect that any normal person would want that funding to be enhanced to fund the quality of care? What is causing it not to happen?

Ms HARVEY: Again from my observations, it appears that funding gets released in stages and also in numerical terms. For instance, ADHC have a program called Active Ageing and Life Choices, which is enhancement funding for individuals to be involved in community participation. We are accredited as a provider of those services. When I approached ADHC regarding the availability of those packages, I was told the number of packages of funding that have been released to the regions. Newcastle got 13 packages. That meant 13 people in the Newcastle region were able to apply for that funding. That is a drop in the ocean. Certainly, when I contacted Metro North regarding the release of that funding, I was told that there was no more funding available for people with physical disability. So we were unable to apply.

CHAIR: As a measure of trying to come to grips with unmet need, would any of that information assist us in our deliberations in trying to make recommendations to the Government about dealing with unmet need?

Ms HARVEY: Yes.

CHAIR: Perhaps there is some information there.

Ms HARVEY: I think there is some new information ADHC might be able to give you, especially around that program, in relation to the number of actual packages that have been released against the number of people living with a disability in New South Wales. If you have a look at that, then you would be able to see the discordance between that.

The Hon. GREG DONNELLY: You may not wish to answer this because you have covered it, but this paradigm of thinking of people with disability being encouraged to be able to exercise that autonomy and choice over the way in which the moneys they receive to support them in their situation is spent to look after them over the long-term. I continue to find that is an interesting and difficult tension to manage. On one hand it has been put to us by some people giving evidence and in submissions that as a society we need to respect that autonomy and that right of individuals, and people with disability are not to be excluded from that, and I support that in principle. But it has gone even further, and some people have argued that they should be entitled, at least conceptually, to make mistakes in the way they make decisions in terms of how money is expended or how they are looked after. On the other hand, the cookie-cutter approach of the past, of having a one size fit all, is something we have moved away from, and how we strike that balance in the middle in the best interests of people with disability is obviously a challenge. I welcome your comments or thoughts about that, particularly from your organisation's point of view on how you see this balance being achieved.

Mr BOSOTTI: I think it is a difficult one because there is so much individual input into that decision-making process. Clearly, people will make mistakes, but from my point of view we are hopefully moving away from the cookie-cutter approach and providing a range of choices, whether it is in accommodation or in service provision. I think we need to have a full suite of choices for those individuals to make, and no doubt there will be mistakes made—

The Hon. GREG DONNELLY: Sure.

Mr BOSOTTI: —in that process. But I think, certainly from the accommodation standpoint, I am strongly of the view, having seen and been part of those discussions regarding some of the accommodation models, that we need to offer those different choices, and the same with the services, whether they are self-directed—there seems to be an emphasis on that and I think there needs to be a little more flexibility.

The Hon. GREG DONNELLY: I will pick up on that because a number of witnesses have touched on this package program that is being thought through as the way in which these things are managed in the future.

Is what you have just said your essential position that the individual package notion is the way in which we should be looking at the management of these matters with people with disability?

Mr BOSOTTI: Certainly that is the way that we should be moving in providing that choice, if that is what your question is.

The Hon. GREG DONNELLY: Yes.

Ms HARVEY: I was just going to comment in relationship to future planning that there is a lot of bureaucracy in terms of policy and frameworks and eligibility criteria around a whole range of different ADHC programs. There certainly is a lot around Health as well. There is also a lot around Housing. I think we need a communion of agreement between Health, Housing and disability sectors because historically ADHC has worked in the community sector with Community Services but it certainly has not worked in a partnership way with Health and Housing around delivery of funding.

The Hon. GREG DONNELLY: I think the phrase is "whole-of-government approach". We have heard that a few times.

Ms HARVEY: Yes, I have heard that a few times. But it is time that those barriers were brought down because there is a lot of waste of resources and people who fall through the gaps.

The Hon. GREG DONNELLY: And also between State and Commonwealth as well?

Ms HARVEY: Absolutely.

Mr BOSOTTI: I think that is probably the most fundamental. We raise it in our submission but I think that coordination between those various departments is probably the essential in looking at the whole life cycle of an individual in terms of what their requirements are and how each of those departments can collaborate to achieve an outcome. The important thing is to recognise that a person with a disability, their needs will increase over time and they are living longer. I think the two fundamental points that are sometimes lost somehow is that needs are not static. A person in their 20s may have a certain set of requirements that will increase over time as they age, and the only way that I think that can be adequately addressed is if all those parties that are involved can coordinate their activities in a way that the outcomes are delivered.

CHAIR: So we do not replace one size fits all with one size fits all. We need a mix and balance and an ability to mix and match. Sorry, I do not mean to be putting words in your mouth. That is not what I meant. Thank you for your time and your expertise this morning. It is very helpful. Your submission has been extremely helpful to the Committee. We greatly appreciate it.

Mr BOSOTTI: Again, thank you for the opportunity of addressing you.

(The witnesses withdrew)

(Short adjournment)

STACEY SHEPPARD-SMITH, Executive Officer, New South Wales Home Modification and Maintenance Services State Council, and

SHALLA THOMAS, Chairperson, New South Wales Home Modification and Maintenance Services State Council, and Service Manager, Coffs Harbour, Home Modification and Maintenance Services, and the Service Manager for the mid North Coast Home Modification Scheme, and

STEPHEN ROBERT MALVERN, Vice Chairperson, New South Wales Home Modification and Maintenance Services State Council, and also the Project Manager for the statewide level three project, sworn and examined:

RUTH MARGARET LEY, Secretary, New South Wales Home Modification and Maintenance Services State Council, and Service Coordinator, Builder, Blue Mountains Home Modification and Maintenance Services, affirmed and examined:

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

Ms SHEPPARD-SMITH: On behalf of the Home Modification and Maintenance Services. We are a statewide project based in a regional centre.

Ms THOMAS: In my stated capacity with Home Modification Services.

Mr MALVERN: With the Home Modification Services.

Ms LEY: If it is acceptable I will be speaking in both roles. Our service put in a submission as well as State Council put in a submission.

CHAIR: Do you want to make an opening statement?

Ms SHEPPARD-SMITH: Yes, absolutely. We thought we would provide the Committee with an overview of the Home Modification and Maintenance Services industry. The Home Modification and Maintenance and Services industry provides support to clients. We modify people's homes so that they may remain in their homes and remain independent but we also provide support to other HACS services so that they may go in and provide care services. A modified bathroom will assist home care, for example, in going in and providing personal care services to clients in their homes. We have three levels of service provision within the home modification and maintenance services industry. There is level one, two and three. The work is reflected on monetary bans and work progresses through the system according to the cost and the level of complexity.

Level one is between the value of $0 and $5,000—sorry $7,500. Level two is work that is more complex and is between the value of $5,000 to $25,000 and level three which is for the clients who have high complex care needs is for the value of $20,000 and over. The New South Wales Home Modification and Maintenance Services State Council is the peak organisation for Home Modification and Maintenance Services in New South Wales. There are 106 home modification services. State Council's key focus is capacity building initiatives such as training and resource development for occupational therapists, builders, trades people and service coordinators. We also are a bit different from other peaks in New South Wales because we provide a quality assurance program which actually regulates the home modification and maintenances services in regards to the quality of the workmanship that has been completed in clients' homes.

CHAIR: As the peak body you give the service of quality control on your members?

Ms SHEPPARD-SMITH: Yes, that is correct. We regulate the industry through our quality assurance program.

The Hon. TREVOR KHAN: What level of funding do you receive from ageing and disability services?

Ms SHEPPARD-SMITH: Are you talking from a state-wide perspective for home modification services or the New South Wales Home Modification and Maintenance Services State Council?

The Hon. TREVOR KHAN: From the latter.

Ms SHEPPARD-SMITH: It has varied throughout the years. The first lot of funding that the New South Wales Home Modification and Maintenance Services State Council received was in 1998 when the Home Modification and Maintenance Services Program diverged from the Department of Housing and it was then under the Ageing and Disability Department [ADD] at the time. We first received contingency funding and regional technical advice funding, and to this present day our fixed term recurrent funding that we receive from Ageing, Disability and Home Care totals approximately $200,000, but since that time, since the very first instalment of funding, we have received instalments of non-recurrent funding for specific purposes throughout New South Wales, mainly to reduce waiting lists for home modification and maintenance services because there is a high demand for our service. We have also received funding for non-recurrent occupational therapist [OT] brokerage funding, which actually brokers private occupational therapist assessments to assess clients in their homes and we also receive non-recurrent funding to administer and regulate the quality assurance program in New South Wales. So in total it has been about $20 million over the past four to five years because we have received quite substantial amounts of non-recurrent funding because we have recurrent funding shortfalls.

The Hon. TREVOR KHAN: Do you put in an annual application for funding or is it over a longer period of time? How do you justify your recurrent funding?

Ms SHEPPARD-SMITH: Again, this is from a State Council perspective?

The Hon. TREVOR KHAN: Yes.

Ms SHEPPARD-SMITH: Basically, the State Council has identified specific purposes for the funding and we funnel that into the industry, so the money that the State Council gets is funnelled directly into the home modification industry. We always put in funding proposals to the department. Our most recent one was at the beginning of this year for non-recurrent funding for those purposes which have just been outlined, so yes, we have to go through the hoops of constantly putting in funding proposals for the industry for those purposes.

The Hon. TREVOR KHAN: In terms of recurrent funding, do you put in an annual application or is it on a more ad hoc basis or is it to cover a longer period of time? There has been a good deal of evidence with regard to funding applications and the number that people have to put in. I just want to get a feeling as to how much time you spend filling in applications for funding and how much time you then have available to actually do some work?

Ms SHEPPARD-SMITH: It is a very good question and thank you for asking that. With the Level 1 and Level 2 services, they receive recurrent funding, so obviously they are not putting in continual funding proposals because it is recurrent funding. With the New South Wales Home Modification and Maintenance Services State Council we have our fixed term recurrent funding that we do not actually put in funding proposals for, but for the large non-recurrent buckets of money, because they are very large sums and we have to be accountable for public money, we have to put in extensive proposals. Those proposals can take up to two months to put together because we are collecting data from the sector, we are not just saying we need X amount of dollars. We collect statistical information from the services to back up the information within our funding proposals. I know that there is a move towards red tape reduction within the not-for-profit sector, but State Council seems to be very entrenched in a lot of paperwork to receive funding in that regard.

The Hon. MARIE FICARRA: I wanted to touch on the issue of waiting periods. A number of submissions have been quite critical of the time that it takes for clients to access home modification. How does your organisation generally proceed with these cases? Do clients initially contact you, and how long does it take to get their home modifications installed from that initial contact?

Ms SHEPPARD-SMITH: To keep it in context, I will give a very quick overview and then the others, because they work within the level system, will be able to give you more information. It starts very basically with an occupational therapist assessing a client, and the KPMG review of the home modification and maintenance services industry that took place in 2005 actually identified that part of the longest waiting period was for an occupational therapist assessment to take place because the occupational therapists sit within NSW Health and they have competing priorities and clients on waiting lists, so the client must be assessed by an occupational therapist in the home and then they refer that client on to a home modification service. The home modification service then prioritises that client in between their existing current workload and priorities, so it could be that they might have shortfalls in recurrent funding and might not be able to service that client at that particular time. They may have to source an external commercial contractor and that commercial contractor has commercial priorities that they must meet as well. So they are trying to fit the home and community care [HACC] client in amongst their own competing workloads, and there could be other factors where it is a major modification, so it then has to go to the Level 2 and through the Level 3 system where it is assessed by regional panels, so there can be time delays in receiving home modification, yes.

The Hon. MARIE FICARRA: I will go to the Blue Mountains submission because it deals with the issue of occupational therapists. Ms Ley, in your submission you raise concerns about the quality of referral from the occupational therapist to your office. Can you tell us a bit more about the problems there and perhaps any recommendations to improve those issues?

Ms LEY: What works best for us at level 1, which is the basic service, is if the occupational therapist is employed either by the home mods service or by community health so that they are part of the community and can refer to other services very easily, they have knowledge, past and present, and access to everybody's general knowledge. What happened with our service recently was we had access to the brokerage that Stacey was talking about to hire private occupational therapists to reduce the waiting list, because the waiting list is usually with Health. In the Blue Mountains it has been up to 18 months.

The Hon. MARIE FICARRA: What happens to these clients in between times?

Ms LEY: Nothing—they wait. They do have the choice of getting their own occupational therapist and their own builder, but we proved again, without being too critical of the occupational therapists, that they are not doing home modifications in private homes all the time. They are not referring to other community services so their skills are not up to the job. We are spending a lot of time following up and in some instances it is very difficult to get any accountability for the quality of the work through the private contractor, so to speak. It showed again that just throwing money at it is not going to solve the problem. We have to have the quality of the OT there.

The Hon. MARIE FICARRA: Are there other States that do it better with better guidelines? I am thinking about what sort of recommendations we can put forward to improve this system, both the time frame and the quality of the work. Is there anywhere we can point to that does it better? Are there any particular guidelines or recommendations we can make?

Ms SHEPPARD-SMITH: From a national perspective home modification and maintenance services are run vastly differently from one State and Territory to another. To give you a quick overview, in Victoria the HACC funding is mainly auspiced by local government and there is a $4,000 cap on service provision. New South Wales has the most complex and evolved system there is and varying auspicing organisations hold the funding. In Queensland it comes under Housing and in South Australia it is a similar model to New South Wales. Tasmania has also based its model on the New South Wales model. Western Australia and the Northern Territory are not very evolved. Currently ADHC has engaged consultants to review the home modification and maintenance services industry so that we can address some of the issues at hand. It has been quite a reactive process because we have been so vocal about the issues. Getting back to your other question, I am not sure whether there is another model within Australia that we could look to. Perhaps New South Wales is leading the way and we just need to refine the model we have and most definitely improve all our guidelines.

The Hon. MARIE FICARRA: Do we have enough occupational therapists? I know the training they have to do for this particular job can be improved, but is there also a lack of OTs?

Ms SHEPPARD-SMITH: We have two competing scenarios in New South Wales. In the metropolitan area we have a huge number of occupational therapists that we can draw from. A lot of them are young new graduates coming out of university and so they are quite inexperienced, but there is a high demand for service because of the population so there are huge waiting lists. Sometimes people can wait anywhere from 12 to 18 months for an OT assessment. In the regional and rural areas of New South Wales we have a very limited pool of OTs. In some areas there are just no OTs available at all. That is where the non-recurrent OT brokerage funds were used from a State Council perspective because we funnelled them into the areas where no occupational therapists were available so we could engage private OTs to assess clients in a more timely fashion. That is what it is about, trying to provide an efficient and effective service in a timely fashion.

The Hon. MARIE FICARRA: It is not viable to force those people from country areas to come to metropolitan areas for assessment?

Ms SHEPPARD-SMITH: No.

Ms THOMAS: Alongside the OT brokerage funding there was also a whole lot of training packaged in with that. To elaborate on Ruth's comment about the inexperience, we have also packaged a lot of training and so there are private providers as well as Health-funded OTs in there who are gaining a lot more experience because of the training work we have done around New South Wales. It had to address both issues, funding and experience.

The Hon. MARIE FICARRA: Ms Ley, you looked as though you wanted to add something.

Ms LEY: I was just going to say that the significant thing is that OTs come out not trained to do home mods.

Mr MALVERN: Especially major home mods. One of the things we would like to see, and which we continue to ask for, is that an occupational therapist should sit with each level 2 service so that they get some expertise in the type of work we are dealing with, which is the work over $7,500, and that we get some consistency in their referrals.

The Hon. MARIE FICARRA: Could this be part of their training as well as ongoing?

Mr MALVERN: It would be nice to see the home mod services funded to engage an occupational therapist permanently and that they then work with the group of builders and the referrals become consistent in their approach and the occupational therapists have some expertise in building knowledge. There are two professions working against one another. Basically home mod services are builders and then there is the medical side. I consider home mod services to be prescription builders. We will only work to a prescription, hence the two are so closely knitted together yet it is fragmented because we are dealing with young occupational therapists who basically have very little knowledge of home modifications. Ideally the two should come together. Whilst State Council is trying to upskill home modification services around the trades aspect we are also endeavouring to train occupational therapists. Ideally, if those OTs sat with the major modification services there would be some knitting together and some understanding of building knowledge and what we can and cannot do. Some occupational therapist recommendations simply cannot be done from a building perspective. Not only that, there is the added complication of occupational therapists basically overservicing. In other words, from a builder's point of view we could come up with the same outcome at half the expense.

The Hon. MARIE FICARRA: So currently occupational therapists and the relevant builders servicing the client hardly ever get together face to face for a dialogue?

Mr MALVERN: Absolutely. We have even had modifications where there are no joint visits. It is fragmented. When we get into major modifications they sometimes drag on and several OTs are involved with one project. By having an OT sit with a home mod service we rid ourselves of this ongoing problem of a different face to talk to and comments such as "The previous OT recommended this and I'm not quite sure that's what we want". We go down a never-ending path.

The Hon. MARIE FICARRA: It does not sound very productive really. It could be improved.

The Hon. TREVOR KHAN: How many modifications of the sort you are talking about are being done?

Mr MALVERN: I manage the level 3 service, which is the statewide project—anything over the value of $20,000. Level 2 services can hang onto modifications up to the value of $25,000 if they have the funding and the expertise to carry them out, but basically they are meant to flick them to our service at $20,000. We are so dependent on funding we cannot meet demand. When we were in a position to meet demand we carried out 75 home modifications over the value of $20,000 in the State.

CHAIR: That was meeting demand?

Mr MALVERN: We were able to meet demand. The statewide project is currently funded $1.7 million. The average home modification at our level runs at about $38,000. It varies slightly. The year that we were able to meet demand we drew on the non-recurrent funds that were provided to State Council and we did almost $3 million worth of work.

The Hon. TREVOR KHAN: Does that mean that at present, if it is $1.7 million as opposed to $3 million, you are doing something in the order of 40 modifications?

Mr MALVERN: Yes. Last year we were able to do 50. Remember I am not talking about the jobs between $7,500 and $20,000, I am only talking about those over $20,000. If you ask me how much money we would need to meet demand, my answer at this stage would be $3 million.

The Hon. TREVOR KHAN: Per annum?

Mr MALVERN: Per annum, recurrent funding, and that would come somewhere close to meeting the demand.

CHAIR: For grade three?

Mr MALVERN: For anything over $20,000.

CHAIR: When you call it grade three—

Mr MALVERN: No, sorry—level three.

Ms SHEPPARD-SMITH: You have a copy of my annual report. On page 14 it states that in the 2008-09 financial year we completed 318 major modifications in New South Wales, but we still had a waiting list of 5.6 million.

The Hon. TREVOR KHAN: With regard to your retaining an OT on your staff, they deal only with level threes, is that it?

Mr MALVERN: No. There are current 12 level two service providers of all regional providers around the State. We have an imbalance. Some of them have OTs on the staff. We have one particular service that has something like nine OTs and only one builder. We have other ones where we have 15 builders and two OTs. Then we have approximately nine level twos that do not engage an OT in-house. Correct me if I am wrong.

A recommendation that we have been pushing from a peak level is the thinking that an OT is an integral part of the building process and there should be funding available for each regional service, or each level two service, to have an OT on staff. Then we would provide all sorts of consistency around the State and we are not basically training these occupational therapists about home modifications.

The Hon. TREVOR KHAN: I was wondering, if you had one employed at your level, how you would cover the whole State. I am from a country area.

Ms THOMAS: Some of the regional projects, the level two budget holders, did get some brokerage funding to sit with their project for occupational therapists, but in that you are still having to engage private providers. I am from the mid-North Coast. There are a lot of OTs missing in the southern part of the mid-North Coast, but when you do engage an OT using your brokerage dollars, the quality of application varies vastly.

Our panel has two occupational therapists who sit on our review panel for those applications. They become pseudo-advisers for the region because there is no so-called expert sitting in that area. So it is then deflected back to the specialist occupational therapist that sits with State council. But if we had somebody and we wanted to employ somebody, we would be told, "No, you've got your brokerage model. That is what we put up to State Plan, so that is the way you have to make it function", but we are going, "No, the employment model is a much better outcome at the end of the day for the clients." It would be much better if we could get enough funding to have OTs sitting with those major complex service providers because it works much better.

The Hon. TREVOR KHAN: What is brokerage funding?

Ms THOMAS: It is a non-recurrent bucket of money that is given to you to purchase private providers. It is not enough to actually employ a person in that position, but it is enough to just purchase events of provision of service.

Ms SHEPPARD-SMITH: You cannot actually employ because of the nature of non-recurrent funding. It is a one-off instalment so you have to have fixed-term contracts rather than long-term employment contracts with people. It is quite problematic in that regard, even though it is a quick fix and it is a bandaid solution by being able to get private providers in. It does not build technical capacity or skill or knowledge within the region because we are accessing multiple people at any one given time.

CHAIR: Stacey, you mentioned the issue of the 2005 KPMG review.

Ms SHEPPARD-SMITH: Yes.

CHAIR: Are you able to tender that document?

Ms SHEPPARD-SMITH: Yes. I have a copy of that. I can most definitely send that to Emily. That is absolutely fine. I have it on record.

The Hon. HELEN WESTWOOD: Ms Ley, earlier you said that the waiting time for your service is about 18 months and that is with Health. By that did you mean that it was because you are waiting for an OT?

Ms LEY: That was the waiting time at intake of Health for an occupational therapist. The client rings in, they take their number, and then they are put on the list. Then the occupational therapist comes out.

The Hon. HELEN WESTWOOD: That needs to happen before you can proceed to offer them a service?

Ms LEY: That is right. The occupational therapist sends the referral.

The Hon. HELEN WESTWOOD: To you?

Ms LEY: And then we go out, yes.

The Hon. HELEN WESTWOOD: It is not that someone comes directly to you and you engage the OT via Health?

Ms LEY: No. In our region, that is not how it works. In our region they go through the intake and then are either sent to the ACAT team or community health OTs. But during that brief trial that I mentioned in my submission, we were asking clients to ring us directly. It is interesting because we got a really good idea of how many of them are not getting service—the real waiting list.

Ms SHEPPARD-SMITH: There is a substantial amount of HACC funding that is going into Health through allied health services. Why are there such huge waiting lists with Health? We know they are under strain, but it is an issue that really needs to be addressed so that there can be more timely service provision to clients who require home modifications.

Ms THOMAS: If a client contacts a service directly and it is for a modification, it has to go back to an occupational therapist to get the prescription for us to proceed anyway. Again you can be going back into an aged care assessment team which has perhaps a six to 18 months wait list, so that client will be sitting on their waiting list before they come back. Maintenance is a different issue.

The Hon. HELEN WESTWOOD: You have mentioned that graduate OTs really do not have the expertise or knowledge that your clients require. Have you had the opportunity to talk with any of the universities about their curriculum?

Ms SHEPPARD-SMITH: Yes, within NSW Home Modification and Maintenance Services, we have two specialists. We have a specialist technical officer, Keith Stevenson, and our specialist occupational therapist, Marg Newson. Marg is a very experienced practising clinician. She has a Masters in Education. We work closely with OT Australia, New South Wales. We asked OT Australia, New South Wales, to lobby the universities on our behalf to see if environmental modifications could be made a part of the curriculum, but they did not: they felt that, because there were so many different specialties within the occupational therapy realm, they did not think it was something they wanted to lobby for. We would most definitely like to see environmental modifications in all the universities' curriculums. Any help we could get with that would be fantastic.

The Hon. HELEN WESTWOOD: You were not able to go directly to the universities yourself?

Ms SHEPPARD-SMITH: We went through the occupational therapists peak organisation, thinking that that was the best avenue to take—for them to lobby on behalf of occupational therapists. But most definitely we can go to the universities and address it with them.

The Hon. HELEN WESTWOOD: You referred to the value of the work or modifications. Is that made up of materials and labour?

Mr MALVERN: Yes. That is basically the commercial value of the work. It depends. To provide services right across the State, some home modifications services engage in the work themselves and others contract out the work to subcontractors. It might be that we would give the work to a builder to execute, or it might be that we subcontract the work to tilers, plumbers and electricians and take control of the work ourselves. It just depends where the expertise is and who we have got to do the work.

The Hon. HELEN WESTWOOD: How many of these services employ a builder on the staff?

Mr MALVERN: This is one of the biggest issues we have. If I may, you questioned the quality assurance program that State council runs. The reason behind that is that essentially we are all builders. By law, we are meant to have a builder's licence to undertake the type of work we do when the value of work exceeds $1,000. Unfortunately, of the 106-odd home modifications services out there, there are approximately 40-odd services that continue to remain unlicensed. Basically they do not have the technical expertise to undertake the work that they are funded to do. This has been brought up with ADHC over many years and they continue to fund these projects. In 2006 under the building Act, we must provide a statutory warranty on all the work we do up to a period of seven years.

The Hon. TREVOR KHAN: That condition is attached to your licence.

Mr MALVERN: That is right.

Ms SHEPPARD-SMITH: That is correct.

The Hon. TREVOR KHAN: Without a licence, you do not have statutory cover. Is that not right?

Mr MALVERN: That is right, yes.

Ms SHEPPARD-SMITH: That is correct.

Mr MALVERN: In 2006 we obtained an exemption from providing home owners warranty insurance. Part of the reasoning around the exemption is based on the government body that was funding our project, which already had a quality assurance program in place. There is a total misunderstanding with ADHC about providing consumer protection as we, by law, have to do in respect to building works. The quality assurance program that they believe they have in place is something quite different in respect to having policies in place around providing a service for different types of clients.

At no time, not even as part of the tendering process for providing you money, do they ask the question whether or not your service is licensed to undertake the work they are funding you to do. At the same time, State Council are running around providing a quality assurance program, which is basically fixing up a lot of the work that has been done, and defective work that has been done in some cases, by home modification services. We continue to have this battle with ADHC so that they gain some understanding of the type of work we actually do. A lot of the work is complex and not simplistic. We do have cranes in streets. We are lifting lifts and taking roofs off houses and putting lifts in residential homes. We are doing major works in some cases. Yet, I do not believe they understand the complexity and the reasoning around us having to provide some consumer protection.

CHAIR: In regard to all three levels or is this just level one?

Mr MALVERN: No. They have changed it, but currently, anything over the value of $12,000 should have home owners' warranty. Not only that, if we do work for a HACC client and they die 12 months later, we are still responsible for that work up to a period of seven years. The volume of work that we have out there in the industry is currently about $40 million over the previous seven years. It has to be remembered that the damage that is likely to be done from perhaps a defective waterproof membrane in a bathroom is not just the cost of the work that we undertook. The $15,000 bathroom may well do $50,000 worth of damage.

Ms SHEPPARD-SMITH: From a historical perspective, the program has evolved over the years and the funding is allocated right across the State, and there are varying levels of funding. Part of the issue with licensing is that there are some smaller services, for example in the Riverina Murray region and the Southern Highlands region, that receive really small buckets of funding, like $7000 and $10,000 to provide modifications, but because of the levels of funding, they cannot meet compliance issues, such as licensing, to be able to employ builders, and there are issues such as asbestos management. We have identified this with ADHC on many occasions, that you keep funding these people but they cannot meet compliance, and, as such, they are breaching their funding agreements, but they continue to fund these services, even though we keep highlighting it to them.

The Hon. TREVOR KHAN: How do you highlight it?

Ms SHEPPARD-SMITH: We have face to face meetings. I have tabled some documents for you. We usually have ADHC representatives attend our quarterly State Council meetings. We talk to them about these issues. Sometimes there is a clear lack of understanding from ADHC representatives. What is also problematic is that there is a high turnover of staff within ADHC. So there is no corporate knowledge that is passed on. We are constantly re-educating members within the department in regard to home modifications. We also provide letters on issues. That very top cover letter there contains all the issues that are constantly brought forward but are never addressed. I am sorry, it is an e-mail.

The Hon. TREVOR KHAN: I know I am doing this with the leave of the Chair. Is the licensing issue identified in any document contained in the bundle that you have provided?

Ms THOMAS: Yes, several times.

Ms SHEPPARD-SMITH: In the KPMG report it was identified as a driver of change, in the KPMG review of 2005. We had one ADHC representative back in 2005 who tried to resolve it with us, but she moved on to another department, so it never was resolved. There are many home mod services, 40 in fact, that are not licensed under the Office of Fair Trading licensing requirements.

Ms THOMAS: Some of the auspices are an issue around that as well. Some of those home mod services that sit within Health and local government can actually operate and function without licences because they come under a different brief, and so they are still functioning in non-compliant ways as far as the rest of the industry is concerned because they have that departmental loophole.

Ms SHEPPARD-SMITH: Hence, we have had to implement a quality assurance program to regulate the industry for all major modifications in New South Wales, to make sure that we have got quality client outcomes.

Mr MALVERN: Can I just add there that this is the same quality assurance program that ADHC has just chosen not to fund. The State Council as a peak body has decided to keep that quality assurance program going for a further 12 months in the hope that we can convince ADHC that it is actually a consumer protection program that by law we must provide.

The Hon. HELEN WESTWOOD: What are the demographics of your client group that require modifications in each of the levels? Is it a different cohort in level 3 as opposed to level 1?

Mr MALVERN: I can only speak from a level 3 perspective. I have kept some statistics—only for the previous two years—in respect to where our money is going with regard to disabilities and frail aged. It has been consistent over the last two years that 74 per cent of our funding—72 per cent one year, 74 per cent the other year—is going to people under the age of 65; 26 per cent of our funding is going to children under the age of 16. I keep those statistics on the basis that I think some of the modifications we are doing are there for many years.

Ms THOMAS: In two, the lower level scheme, it would be mainly frail aged people, the smaller cost frail aged. There is a higher cost for younger people with a disability.

Ms LEVY: We find the children with disabilities that we deal with in level 1 seem to be in rental accommodation. So we are not doing major works there anyway. It is a whole different ball game. It is predominantly aged, level 1.

The Hon. HELEN WESTWOOD: Our emphasis has been on modification. I am just wondering about maintenance as well. What sort of issues are you facing in terms of providing maintenance? Do you employ your own builder or handyperson for those works or do you contract that work out? Secondly, what types of modification predominate in the requests that you get?

Ms THOMAS: Maintenance can be a very high cost or a very low cost. The lawn mowing is a fairly recent recurrent maintenance issue that we have. Again, one of the high priorities for clients in their homes is the lawn mowing and garden service, but if you have a maintenance issue around plumbing, it can be very high cost. Those things have also been capped. We started out as maintenance services, but the modification has taken over in that and the maintenance has got left behind as far as the funding. ADHC has now separated the two out so that we have a modification stream of funding and a maintenance stream of funding. The maintenance has fallen behind. Yet it is a high priority for people remaining at home, because they are the biggest issues. We try and maintain a focus around safety and access. That can be quite broad in relation to guttering and rooves and access points. Those roofing things and the plumbing can be very high cost, but it is something that is essential to keep people at home.

Mr MALVERN: Things like sewer chokes and replacement of hot water services, that type of thing.

Ms THOMAS: As it is being identified as hourly, in relation to statistical information, we were asked to report that on the basis of hours of service provided rather than dollars, and it does not really reflect what is actually happening. If it could be reported as a dollar factor it might actually show that the cost of providing maintenance services can be quite high as well.

Ms SHEPPARD-SMITH: And that information is in the information that we have tabled today. We have flagged that with the department on a number of occasions, the inconsistencies between modifications in dollars and maintenance in hours with the minimum data set but we have had no resolution on that issue. Our planning is important but they need to be consistent in their approach with modification and maintenance.

CHAIR: Would you like to give us some ideas on recommendations? Any ideas you might have would be greatly appreciated. We probably have a few questions we will need to send you on notice, with your indulgence.

Mr MALVERN: We got together before this meeting and I think the message that basically we wanted to say here today is our disappointment that the department that funds us has very little understanding of the service we provide. With the transition of staff within ADHC we are continually basically explaining our service to any new staff. A suggestion here would be that ADHC retain staff with a full knowledge of each service that they are providing, in which case we do not—the submissions we have just asked for, we had to explain, in pretty much the same way we did here today, about the levels of funding, the services and all the rest. It is not uncommon for us to have to do exactly the same thing to ADHC, which is funding us. I guess what we are looking for is somebody within the department who fully understands the projects that it is funding. It is quite sad to say.

CHAIR: In the transition or evolution from institutions, however one may define an "institution"—and there are some rather innovative definitions of that word—and as we devolve to living in our homes, am I right in assuming that you have a pivotal role in ensuring that the place of abode is free of any dangers?

Ms THOMAS: Until universal design is fully embraced, we will be very busy for a very long time.

Ms SHEPPARD-SMITH: Just one last thing I would like to add is that I think planning needs to be improved within the department, within ADHC. As I stated in my cover letter, the minimum data set refers to past episodes of service and it does not capture funding shortfalls and waiting lists and unmet need. We firmly believe that more consultation needs to take place with the services with regard to planning. The regional allocation formula that is currently in place needs to be reviewed because some of the services in the central west and Orana far west regions of New South Wales are severely underfunded because the regional allocation formula goes on demographics. They have a lower population out there but they do not have enough funding to be able to meet compliance issues with licensing. So the regional allocation formula within ADHC needs to be reviewed.

CHAIR: The secretariat will be in touch. Thank you for your help.

(The witnesses withdrew)

ANNE-MARIE ELIAS, Policy and Communications Manager, Council on the Ageing New South Wales, sworn and examined:

RUTH ROBINSON, Executive Officer, Physical Disability Council of New South Wales, affirmed and examined:

CHAIR: In what capacity do you appear before the Committee? Do you want to make an opening statement?

Ms ELIAS: Yes. The Council on the Ageing [COTA] New South Wales was established in 1956, and is probably best known for the establishment of Meals on Wheels in Australia. We are a peak advocacy group representing the over 50s across New South Wales. Our core functions include social policy development, representation and advocacy and that is the capacity with which I am here today; to represent and advocate for the over 50s that engage with the Council on the Ageing. One of the key items about which we are extremely concerned, and what we will talk throughout our session, is ageing in place. We hear resoundingly from older people that that is actually a priority for many older people: They want to age in place. Therefore, many of the services that are currently offered by Ageing, Disability and Home Care actually enable people to live at home for as long as possible.

We are also very passionate about prevention and early intervention, again enablers to ensure that we pick up concerns and needs of people early on to actually prevent them entering residential care if as a last resort. We also believe very much in person-centred approaches. You will see throughout our submission we very clearly state that we represent not only non-English speaking background older people who are ageing, in fact, more dramatically than the Australian population but also the older gay and lesbian, transgender and bi-sexual communities who are also ageing. If we are true to our rhetoric that we believe in person-centred approaches those particular needs will be reflected in service delivery. So that is why we are passionate about the notion of person-centred care to meet a varying range of needs of our older people.

We also believe in client choice and seamless experience of service for clients so whether they have a disability or not that they should experience a seamlessness of service and be able to move through the system and get their needs met. Within that is also, therefore, a need for flexibility of service delivery and perhaps more engagement across State and Federal services to ensure seamless service provision. Finally, we are absolutely clear that funding to Ageing, Disability and Home Care needs to be in tandem with the increases that we are fully aware of of the ageing population. We do not feel that that has actually happened and so our clear recommendation will be that you have an enormous opportunity through this inquiry to ensure that adequate funding is allocated. We know the data about the ageing population so we do not need be blind to that reality. They are the key areas for COTA New South Wales.

Ms ROBINSON: For the Physical Disability Council of New South Wales we are also a peak organisation for people with a physical disability in the State. We have not been around as long as the Council on the Ageing [COTA]. It was in the mid 1990s when this peak body was established but I guess that reflects the political times in the 1990s. You might wonder how we were able to represent people with physical disability in the State. The Committee has looked at me and I clearly do not have a visible physical disability which you might be wondering about but I need to say that our organisation takes very seriously its responsibility to connect with people around the State. All of the board of management, the committee of management of the organisation, some 15 of them, are all folk with a physical disability. I am the only person employed in the organisation who does not have a physical disability.

We regularly connect with our community by running specific issue consultations, community consultations, focus groups around the State. We use a lot of strategies to do that: face-to-face meetings, interviews, Facebook, website, questionnaires, surveys and research. So that provides us with a certain legitimacy about understanding what is happening in various parts. We agree entirely on some of the focus of some of the things that we are concerned about are also those things that COTA are concerned about which is why you have two peak organisations placing a submission before you together. It does not always happen but clearly a lot of our concerns are similar. An additional item I want to raise is the impact of ageing on the needs of those people with a physical disability because that is really starting to play out very significantly at the moment. We also took the opportunity in our submission to highlight the variation in service provision and service capability across various areas of the State, the differences of what you might be able to get in terms of support, whether you live in metropolitan, rural or regional areas.

We are also very concerned—and folk with a physical disability have told us—that our funding arrangements and service provision need to be person-centred, not service-centred. That is an item we have in common with the Council on the Ageing [COTA]. Also we hear a lot and have concerns about the business of complaints, transparency of service provision and how perhaps some of the auditing mechanisms that are used could be better utilised to inform people with a disability so that they can think with more knowledge and more information about what they may or may not be choosing to do. Thank you for the opportunity to be here.

CHAIR: Thank you for being here.

The Hon. GREG DONNELLY: Thank you for coming today to provide evidence additional to your submission. I have the benefit of having some questions in front of me that help prompt some elucidation of material in your submission. Through this inquiry we have been trying to get a better understanding of the level of unmet need for services provided or funded by Ageing, Disability and Home Care. It has been interesting to read—and we have had it put to us by a number of people—some of the statistics regarding unmet need in your submission. For example, there were 1,700 requests from carers in crisis seeking support accommodation in 2008, but only 112 places were available. Do you know the source of the statistics that you referred to in your document? Part of the difficulty that has come through from various witnesses is the big question mark over getting accurate data about the issue of unmet need.

Ms ROBINSON: You will find that referenced in the submission. It came from a report from Working Carers, which is just an organisation.

The Hon. GREG DONNELLY: Do you know much about that organisation?

Ms ROBINSON: No, I do not know a lot about it at all, to be perfectly honest. I do know more generally about the carers associations, if you like, and carers groups. That has been an area of great concern for folk with a physical disability because there is a strong community focus on the needs of carers currently and sometimes it is considered by people with a physical disability that I am associated with that the focus on carers is perhaps at the detriment of those people for whom they are caring. I know that seems like a pretty strange thing and perhaps a harsh thing to say, but sometimes meeting the needs of one of those two parties complicates meeting the needs of the second of those parties. Also there is a great concern that having an unpaid care provider within a family situation can sometimes damage rather dramatically the nature of the relationships between those family members and there is a strong concern and a strong call for funding or individualised funding to be made available to the person with the disability, the person who is the care recipient, so that other services can be purchased so that the relationship is not damaged. For example, if you are a gentleman and your wife is providing a lot of the personal care stuff, it changes the nature of your husband and wife relationship. It changes the nature of parent and children relationships, especially as they get older.

CHAIR: Do you know how Working Carers sourced the figures in the article you are talking about, "No places for our loved ones to go"?

Ms ROBINSON: No, I do not.

Ms ELIAS: I am happy to follow that up and provide that.

The Hon. GREG DONNELLY: If you could take it on notice?

Ms ELIAS: We will definitely.

The Hon. GREG DONNELLY: Obviously there is an assertion about the number of requests versus the places which amounts to around 1,550 people in crisis. Do you have a view about how these people are to be given appropriate support in those circumstances? What would be your view about how government policy should face up to this differential need and deal with it?

Ms ELIAS: I think there was a comment made by the previous group of people that spoke about minimum data sets not reflecting unmet need and I think in terms of policy direction, and for want of a better word, we need to collect a risk register of those people we are turning away. If we start to study and understand those people that we are turning away, it may very well be that it is not Ageing, Disability and Home Care's problem but for the Department of Health and Ageing or the Department of Health in New South Wales to pick up where those people are currently let loose in the most desperate circumstances. I think the only other thing I would like to add, and I know that you are all very well aware of that, but we have a major issue with a lot of culturally and linguistically diverse [CALD] older people who have children with disabilities who have largely dealt with these children on their own, and now they are ageing and they are not able to even go and get their hip replaced because they have never institutionalised their children or hooked up their children to services to provide them with respite. This is an increasing problem and it is a cultural issue as much as it is a personal issues. I think we need to consider what we are doing to our older carers if we are not providing the opportunities for them to handle their own life and their own health.

The Hon. GREG DONNELLY: Given that there are so many non-government organisations operating in this area in terms of interfacing with those with disability and those who care for people with disability, is it not the case that those organisations may well be very helpful in developing a more accurate picture of the need as opposed to a government department trying to come up with some number? Do you have a view about that?

Ms ROBINSON: That would seem to be a reasonable suggestion, but I am not a government person or a non-government organisation provider in that sense. It would appear to me that certainly the Government has maybe only just scratched the surface of the unmet need. For example, this morning, just before I came here, a woman rang me who has muscular dystrophy and she has now discovered that she has another condition that has just been diagnosed on top of that, and this means she is disintegrating very, very rapidly. The new condition is motor neurone disease, so her decline is becoming very, very rapid. She made contact with a provider to see if she could get some additional assistance in the home because her mobility has now reduced dramatically and she cannot care for herself and she was told "No", there was a waiting list of two years and they would not put her on the waiting list for two years because she would be dead by then. To me that seems like we are not really meeting—I admit this woman was not from the metropolitan area, she was from a more rural area of New South Wales, but it suggests to me that as of this morning, in 2010, we still really are not meeting the need. I assume she has had one conversation with Ageing, Disability and Home Care about it and a conversation with service providers, but whether or not that will be listed in their tally about unmet need or not I do not know.

The Hon. GREG DONNELLY: I am not getting ahead of the game and anticipating the thoughts of the Chair and what our recommendations might be, but it seems to me—intuitively more than anything else—that, with all the providers out there creating niche support for the particular groups of disabled people that they assist and represent, it would often be that they, as opposed to a government department, are the first port of call for people to make contact and say, "I've got this disability" or "I know someone with a disability, what do I do now?" If that argument is correct, do you think it would be useful to have some uniform way in which the Government could work with non-government organisations to encourage them to collect this information so that there was a degree of standard across all the organisations, so that it could be aggregated to give a reasonable picture? I appreciate it still does not deal with the people who have not been in contact with non-government organisations or the government itself. Many witnesses have put to us that the quality of the information is not where it is, but I guess I am trying to be practical and think we will never get it perfect, so how should we move toward getting something better than we have now. What should be the mechanism for collecting that information?

Ms ELIAS: I suggest that one really simplistic tool—we requested this in our 2010-11 pre-budget submission—is that the Ageing portfolio in New South Wales really ought to put together a funding and services matrix on ageing. At the moment, ADHC funds certain services, Health funds certain services, and local government funds certain services. There is a responsibility on Government to be a leader in this area and set the standard in terms of developing policy. Although the majority of funding is actually carried by ADHC there are several government agencies across New South Wales that provide bits and pieces of funding. Then of course there is the overlay of the Federal Government. In my opinion it would be up to the State to collect that information. Also, if something is being funded by the Department of Health and Ageing [DOHA], why would you want to re-fund it in New South Wales? If something is about to be cut off in New South Wales, why would you not have a conversation with a range of stakeholders to see who is going to pick it up? Quite often we cut things loose without looking at the impact on the community that we are cutting loose and we certainly do not make enough of an effort to see whose responsibility it is to take it on. We understand that the State has a dire situation financially and we are not expecting them to deliver everything, but we do expect leadership. If something is going to be cut off, what are they doing to ensure that those people are not left out in the cold? They should show some leadership and say they are going to get some heads together, maybe through the Council of Australian Governments, to see who can pick this up to ensure a seamless service for older people.

CHAIR: Would that pre-budget submission assist us in our deliberations?

Ms ELIAS: I can certainly send you that relevant recommendation.

Ms ROBINSON: Getting back to your question, yes, it could have some merit, but I am not certain that this particular government department has a really strong history in gathering clear and accurate information. As Anne-Marie has said, and I think the group before us said, information is provided to ADHC on the minimum data set but it seems to be used just for figuring our whether or not service has been provided—counting numbers, if you like, rather than looking at quality. It is not necessarily used in other ways that it potentially could be used, such as for planning and strategic arrangement.

The Hon. GREG DONNELLY: Are you saying it is used more as a procedural tool for collecting information and ticking a box as opposed to analysing the information and using it for making policy decisions or amendments to existing policy?

Ms ROBINSON: Yes.

Ms ELIAS: What is important is that in your review you are not looking just at ADHC but at its funded services. So if it shows leadership, whether it be ADHC, Treasury or the Office for Ageing that collects this matrix information, funded services should as part of their funding agreement provide data of people that have been left behind. That then provides for better planning in the future. If we know X thousands of people are turned away from respite care or from particular services we can work together to find the best way forward and provide a better service for people.

Ms ROBINSON: One area where ADHC has done some proactive work in the last 12 months that is the kind of thing you are talking about is around therapy services, because a lot of people were seeking therapy services from individual providers. ADHC always assumed that perhaps their large waiting lists were not really reflective of true need. They thought perhaps a person might have put their name down, or put a family member's name down, at a number of different services hoping one would float to the top soon. In fact, as they worked collaboratively with service providers and looked at various lists that existed they discovered that that really was not the case: the cumulative number was the actual number of folk waiting for service.

CHAIR: Have the Stronger Together initiatives looked at the issue of data collection?

Ms ROBINSON: From my understanding Stronger Together has had a very close look at therapy services in particular and is attempting to do some proactive work around that. My understanding is that at the moment they have a working party looking at therapy services and some of the additional complications around therapy services provided in regional and remote areas. The work that has been done so far is certainly positive and we applaud that, but we would like to see a lot more.

The Hon. MARIE FICARRA: Referring to your submission and telecare initiatives, we know appropriate levels of service for the ageing population are a huge challenge ahead of us. Carers NSW have suggested in their submission telecare initiatives to help meet this potential growth in demand. What is your view about telecare in the mix of services available to your client base and are you aware of any other innovative service models that we could look at to reduce the pressure on the increasing demand for services?

Ms ROBINSON: I am not aware that we spoke about telecare. Could you refer me to some part of our submission—

The Hon. MARIE FICARRA: Sorry, it was Carers NSW.

Ms ELIAS: Can you describe it, because I have not heard of it?

The Hon. MARIE FICARRA: It is probably fairer to take it on notice. Can we provide a copy of the Carers NSW submission to Ms Robinson and Ms Elias?

CHAIR: Yes.

Ms ELIAS: One of the things you are suggesting, and I definitely think there is a place for it, is a pathway for older people. There should be a central number that older people can ring so they can be directed to the right service. That is the problem. I had a phone call this morning from a grandmother who was absolutely distraught—it is outside the terms of this inquiry, of course—because DOCS had arrived to take away her grandchildren. I spent about two hours before arriving here trying to link her with various services. She was distraught and her husband was not at home to support her. They both have disabilities. They are in the Blacktown area, so I had to do all the running around to find the best place to direct this older person, who has a disability, to the right support. I found that on this occasion I could direct her to Legal Aid in Parramatta, which has a family law day today, so she could get some support in regard to the legal matters, but there was nowhere I could send her for counselling. I have to direct her to her GP in order that her GP can activate that, or hopefully through the family law people at Legal Aid she could get that kind of support.

Part of the problem for a lot of the grandparent carers that we interact with is that there is absolutely no respite for them. That is a really difficult situation because they are taking on the raising of their grandchildren in their 70s and 80s because of family breakdown and there is very little support for those people. If I had one phone number that I could ring to outline the person's circumstances and they could give me two or three places so that I could set up the woman I referred to it would reduce a lot of unnecessary running around. In particular, if old people in distress had a single port to enter so that they could be directed appropriately it would ameliorate the system incredibly.

CHAIR: I think you made reference in your submission, as have a number of other submissions, to the ultimate respite care, which is leaving your child at a hospital or an institution or some other place.

The Hon. MARIE FICARRA: Relinquishing, you mean?

CHAIR: Relinquishing as opposed to having them taken away—the voluntary and compulsory issue. Do you have experience in that area?

Ms ROBINSON: Yes, I do, not so much in my role now, being involved in the area of physical disability, but in a pre-incarnation I was involved in the community sector as an advocate for people with intellectual disabilities and their families. That was in the 1990s before ADHC, or ADHC as it now is, tried to make some improvement, and that was something "folk" used to do. Folk still do it, but not as much as they did, because people become desperate. Any information I could give you is possibly 12 years out of date, which perhaps is not overly helpful to you, but it is certainly something that has occurred.

Ms ELIAS: I think in all of this we really need to infuse any recommendations with the reality that every six seconds someone around the world is being diagnosed with dementia. Last year Alzheimers Australia did a brilliant report that was developed by local government area and by electorate. It showed the incidence and prevalence of dementia between now and 2050. I strongly urge the inquiry, if Alzheimers Australia is not speaking, to ensure they speak to this.

That is going to stress the system immeasurably. For a lot of people with early onset, they are able to manage their own affairs, but they are not able to ring 50 services. You tell me anyone who is able, in a crisis situation, to find their way in this mess of things. Centralising is really important, at least as a pathway for people.

The Hon. MARIE FICARRA: That has definitely come up repeatedly from service providers and clients as well as ordinary individuals we talked to in the community. It is so confusing. There are wonderful services available, even though some of them are underfunded, but how do you get the proper coordination? How does a poor person who is afflicted with their own disability, or a person caring for someone with a disability, know where to start and know how to coordinate the services that are available to them? Then you have the overlap between different service providers and the inefficiencies that exist.

If there could be one central location that could actually see how the whole thing is working and make recommendations to government bodies on how better to deliver these services, it would make so much sense. I am sure we could be doing things a lot better and much more efficiently as well as communicating what we provide in a better manner.

Ms ELIAS: As you know, Marie, you can add a language barrier to that. It just gets worse and worse. You have a profound core disability and then you have other problems. We do not even have a situation in New South Wales where every service is able to provide telephone interpreters and TTY. It is extraordinary.

The Hon. MARIE FICARRA: You mentioned not only people from a non-English-speaking background but also providing services to the gay community that is ageing. Do you have any information on discrimination, intentional or unintentional, in the provision of services that may exist? I imagine that providing aged residential care apart from service provision can be a vexed question.

Ms ELIAS: We do. We are actually quite avant-garde in that way. We sit on the AIDS Council of New South Wales aged care advisory committee. I believe we are the first mainstream ageing service to do so. We do it very passionately because we are very concerned about this current generation of older people, many of whom are not gay identified. They are very discreet. They are very private. They are proud of their sexuality but they do not wear it on their sleeve. This becomes a huge problem when they attend a service and they have a friend who is visiting them and is displaying affection. It is the attitude of people around them.

There was a beautiful story that I will try to provide for you that I think was done by ABC Radio. I think it was called *Brian and Norm—a love story*. An older Italian gentleman had Alzheimer's and his partner, who was Australian, would visit him daily in this residential aged care facility. The grief that they went through just try to be together was absolutely horrific.

One of the things I am really proud of is that we have linked up ACON to the ageing system and the ageing sector. We have made representations to ADHC and the Office of Ageing so that ACON can build its capacity to work with those departments. We have done that effectively. We also heard a couple of months ago Tanya Plibersek announcing an initiative funded by the Federal Government to fund ACON and aged care services in New South Wales examining aged care services and how they can be trained to understand the nuances of the gay and lesbian community as they age. Obviously there are a lot of old older gay and lesbian people with HIV, which is a disability, so they interact at both levels—as ageing and people with disability.

The other thing to be aware of is that there is a report from Western Australia that I can provide you with a copy of, if you prompt me. The report is titled, delightfully, "We Don't Have People Like That Here". It was a study done by an academic in Perth through funding from lotteries. I love these stories because it shows that it is not actually carriage of government all the time to be providing all the money for these things. That was a visionary project. This person basically rang all the aged care providers in Western Australia to say, "We are doing this project. Can we send you a questionnaire on gay and lesbian people?" The title of the report shows that the resounding response was, "Oh, that's nice, dear, but we don't have people like that here."

What I loved about that report is that it was very pragmatic and very proactive. It was not asking for more money or specific facilities for older gay and lesbian people, but it was calling for appropriate training of services so that they understand the needs and concerns of these people and so that they can become better services. I believe that is actually going ahead. That is how we got ACON to apply to the Federal Government for funding to emulate that project in New South Wales. I am hoping that in about 12 months time we will have a really solid set of recommendations about improving services to that community.

Ms ROBINSON: Anne-Marie referred to the fact that it is about people not looking for separate services, but mainstream services. That is, if you like, the story that is coming through from folk with a physical disability. They are not looking for separate services. They just want to be ordinary people getting on with their lives, like everyone else. Because they are getting older, a lot of the stuff that Anne-Marie is talking about is impacting as well. There has been a big issue in daily dementia services for older folk or people who have dementia because there has been a reticence to include people who have a physical disability—goodness knows why.

Our organisation, Alzheimers Australia and Community Care Northern Beaches have been working collaboratively with a small grant to develop an education package to roll out to people who are coordinators of day activity centres. We are hoping that this will help to change some of those attitudes. As Anne-Marie said, once upon a time people did not display, or were not known. Once upon a time, not that long ago, people with a physical disability were not seen in everyday life in the way they are now. We are rolling out two pilots of that training at the moment. The first of those has been completed, and we are hopeful. It seems to have been taken really well. We will be rolling out the second one very shortly, so it is mainstream services.

Ms ELIAS: It is certainly what culturally and linguistically diverse [CALD] older people have told us. They do not necessarily want separate services. I know that you will understand that with small and emerging communities, they are just not going to have the resources to do it like the Italians and the Greeks did in the past. Their churches actually funded a lot of the things that we see today—the Scalabrini village, for example.

Where I go back to person-centred care is that, if you are just looking at an individual, you are meeting that individual's needs. At the CALD diversity in ageing action forum that we held in May this year, all the people there were basically saying, "If I come in and I have a disability and I am a Greek speaker, surely you just assess me on those particular issues." It is not about the service being all things to all people. You might ring, for example, Greek Welfare and say, "We would love you to have a volunteer come here and read the paper to these people", or, you know, "Do you have a group that maybe we could send this person to so that they are connected to the community?"

I think these things are really important because it is not about reliance on funding solely from the State, but it is about so many services that are funded to provide different kinds of activities. We are not utilising them—to the detriment of the individuals, whether they are gay or lesbian, with a disability, from a non-English-speaking background, or sufferers of torture and trauma.

The Hon. MARIE FICARRA: I am curious about why there is greater difficulty for older men accessing information. I know that men are pretty weak at accessing information and helping themselves anyway, but are we seeing that this could go through into older age care for older men? Do they not have older women that can help them? Do you mean older men who are on their own?

Ms ELIAS: Both, actually. This is the direct result of a report that I am happy to send you, on being prompted, that was done by the University of Western Sydney's Men's Information, Health and Research Centre, "Older Men's Access to HACC". They just wanted to get a handle on it. I am sure Ian will attest to this: blokes are blokes. They do not like help. Unfortunately it is not just the single men. What we found in that report is that even with married couples, if the wife is trying to access HACC, the bloke would be saying, "No, love. We don't need that. I don't think so!" They are actually preventing even their partners from accessing help because they just do not feel that they need to go there.

It diminishes their ability to care for themselves. So there is a lot of work for us to do around that. We are having a meeting next week with ADHC to discuss how COTA and the university can now do something with this report. So much important research is done that identifies problems and even pre-empts solutions, and what happens is we do not end up acting on that research. This research has just been released; it was done last year; ADHC funded it; now we are going to talk about what we can do to deliver on what needs to happen with this particular project so that those issues do not disappear in 12 months time.

The Hon. MARIE FICARRA: It is a big problem because it puts a lot of strain on partners, wives, whatever. In particular it is augmented in a lot of the ethnic communities because of this pride in not wanting to seek out support services and women are left carrying a huge burden trying to cope as they get older.

Ms ELLIS: We get phone calls from those women, "My husband is on the bloody roof. He is 84. He is insisting that we don't need to get a tradie to come and remove the leaves from the roof, but what can I do?" It really is disturbing because it is putting them at risk. They are not really gripped on their entitlement, that this is not a charity, this is not about anything, it is actually about enabling them to stay at home and live really healthy and productive lives for as long as possible.

The Hon. HELEN WESTWOOD: You referred earlier to older people who are caring for grandchildren. Do you know whether or not there are significant numbers of older people caring for grandchildren with a disability?

Ms ELLIS: We do not know unequivocally the facts of grandparent carers in general, whether they are looking after a child with a disability or not. We certainly know that if they have a child with a disability, they have a little bit more support than those grandparents who are caring for children without a disability. One of the things that COTA has been a fierce advocate of is those children are disadvantaged anyway and those grandparents are not under the carers' banner and yet they are grandparent carers, so they do not necessarily interact with Ageing Disability and Home Care unless that child has a disability. Not that we want to pit the two groups against each other. They are both worthy and they both require additional support, but unfortunately there are not clear numbers, and we know—Anne-Marie will probably attest to this—the older CALD communities have really kept this problem hidden and they have kept it very quiet. So what I would suggest is that any data is a gross underestimate of the reality.

Ms ROBINSON: What we do know though is that if a couple have a child with a disability, they are more likely to separate than a couple with a child who does not have a disability. There are statistics around that. I do not have them with me but we could provide them for you.

The Hon. HELEN WESTWOOD: You spoke earlier about carers and how sometimes the focus on them takes away from the person with the disability. Can you say in what way? Are there services that they are missing out on or is it just about advocacy and lobbying and political power, is it that it?

Ms ROBINSON: Some of it is about services. Do not forget it is far more difficult if you have a physical disability to access services than if you have an intellectual disability or a developmental disability. Sometimes people forget that, especially in terms of what is available through government. What I am talking about is often the business of respite. Respite is a complicated thing but a rather fabulous thing. It provides an opportunity potentially for the person who is the recipient of care to have an interesting and worthwhile experience, and it provides an opportunity for those people who are their care providers to do other things in their life and recharge their batteries.

Unfortunately, when you are looking at the provision of respite it becomes a question of: Whose needs are you going to meet? Are you going to meet the needs of the carer and just pop the person somewhere or anywhere to get that break, or are you going to be focussing on the person with the disability? That has become such an issue, that in fact some HACC services now have identified in their funding arrangements that the person that they are providing support for is in fact the carer. Depending how desperate people will become and how conscientious or not conscientious a service is, you may find people who are the recipients of care receiving that respite in situations that are not meeting their needs and are detrimental to them.

The Hon. HELEN WESTWOOD: Is it also an issue then that sometimes that respite care service means that the person with the disability has to leave their home and go to a strange place?

Ms ROBINSON: Yes, that is right. In fact, the business of flexible respite options is probably the approach that is less often taken but the one that has the most potential for success. It is coming back to what Anne-Marie and I have been talking about, which is about looking at the individual and what the individual needs are and building support around that. I am told by people who have tried that in various things that sometimes what you think someone wants or what a service provider thinks someone wants is not actually the thing that they are looking for to create the difference. If you can identify what that is and provide it, often it is a lot cheaper, it is more meaningful and it can do much more positive things in terms of the wellbeing and ongoing sustainability of that person within a community setting.

The Hon. HELEN WESTWOOD: Also one of the issues that we have heard about, in terms of the Committee's work but also more generally in the community, is the issue of ageing carers and their concern for usually their child or their adult child with a disability that they are caring for and what will become of them after that person's death. Most of that focus seems to be on people with intellectual disability. Is there the same issue in relation to people with physical disability, that issue of ageing parents dying and concern about what will happen to the person with the physical disability after the parent's death?

Ms ROBINSON: It is a concern, but also I think it is worthwhile remembering that lots of people with a physical disability themselves are married or in other kinds of situations, they have developed other relationships if you like. We did a survey of people over 50 with a disability who were ageing. We found in that survey that their greatest fear is: What is going to happen when the person who is caring for me is no longer able to provide that care? A lot of the care that is happening for people with a disability is an informal care arrangement, which is why they are probably not even known to ADHC.

We also found in that same survey that of the people who responded to the survey 50 per cent of them were receiving HACC services as the only services they were receiving at all. So it is a very different kind of approach, if you like, than thinking of about some of those huge things, but very important. Still, even if your child has a physical disability and may be living independently, maybe with the support of an attendant care program, or something like that, and holding down a job and getting out and living in the community, often for some people their particular physical disability comes with a certain element of complication that will increase that process of ageing and a deterioration in their general health. Therefore, sustaining that and maintaining their role within the community becomes more difficulty, and they do not have the financial resources to rely on, because given the nature of their disability, some people are unable to work full-time, have to take periods of time off work, have not been able to accrue superannuation in the same way that I have, and that increases that worry about—it is not even just who is physically going to provide support for my family member, but it is how financially are they going to manage it.

Ms ELLIS: COTA New South Wales, with Legal Aid and the Law Society, has been providing a three month pilot called Legal Pathways for Older People, and we have had a few people come through that program who are older people who are caring for a child with a disability. The most heart wrenching situation is when they do not have family and what they are going to do with those children. What I would suggest is a good legal framework to enable them to access legal advice at a free or low cost, so that they can at least talk to a solicitor about making the right provision in the event that they die. It is a heart-wrenching story. My parents run an Italian non-profit organisation. There are huge numbers of Italian older people who are caring for children with disability, as I mentioned earlier, who have never interacted with the care system. They are quite a handful for anybody to take on. Some of the counselling and support the parents receive is the importance of assisting those kids to be as independent as possible because then that provides greater options of who can actually care for them in the event that the parents go.

The Hon. HELEN WESTWOOD: Do you know if there are care arrangements flexible enough to accommodate, say, a carer who becomes unable to care for that person perhaps through dementia or just that process of ageing and they need to go into aged care? Are there services that are flexible enough to then accommodate the person who they have been caring for as well?

Ms ROBINSON: It is a very difficult thing. In fact my other phone call I had this morning was from a person in relation to her mum, and her mum was about 48 and she had a physical disability that she acquired during her life. Her dad had been the carer for this person but dad had suddenly died so she rang the department. Someone told her she should ring the department. She rang the department to see if she could get some support in helping to support her and care for her mum during this intervening period while they figure out what their options are, and they were told, "No, your mother wasn't born with a disability so therefore we won't provide care". That is not exactly correct but it highlights that sometimes having one spot where you go to for information is fine but that information needs to be right. This woman is not old enough yet to go into an aged care facility so they do not want to know about her. She does not have the kind of disability that the person was classically born with so other people do not want to know about it. She does not have an intellectual disability so no-one wants to know there. So she is in a real rock and a hard place at the moment while she tries to work through this.

CHAIR: And in terms of data she is not registered as an unmet need.

Ms ROBINSON: No, she is not.

The Hon. HELEN WESTWOOD: Returning to the point about unmet data and the reliability of it, I think you mentioned earlier the amount of information that is required to be fed back—

Ms ROBINSON: In the minimum data sets you mean?

The Hon. HELEN WESTWOOD: Yes. We have heard evidence from some witnesses that they believe that ADHC should be able to measure unmet need because of the amount of data it is provided with by service providers. We also heard contrary evidence from another witness—obviously they all represent peak bodies—that the data was not that useful. I am just wondering whether you have a view on that.

Ms ROBINSON: It would seem to me that the data that is fed back to them could be very useful if it was mined in different ways, but it is still not going to pick up those folk like we have been speaking about a little earlier who have never presented to a service so no-one actually knows about them. So it will only go so far.

Ms ELIAS: Surely any good provision of service looks at unmet need. Again, maybe perhaps the opportunity through your recommendations is to say that identifying unmet need does not mean that ADHC has to deliver that, that it is actually about ADHC showing leadership to look at who can pick up. We have to stop living in silos. Particularly over the next few years as ageing moves to the Commonwealth and disability remains with the State, we cannot disadvantage people who are trying to move between the two systems or who are forced into one system over another, we cannot have people not be captured in some way and where there is open dialogue and an opportunity for ADHC to say, "Hang on, we need to talk to a few other agencies to see who is going to pick this up." It is about good service planning, it is about vision and it is about leadership.

CHAIR: Do you have any final comments you might like to give us to enlighten us as to some recommendations in this extremely complex field?

Ms ROBINSON: Focus groups have worked with ADHC trying to identify what folk with a physical disability are looking for in terms of potential for service provision through ADHC. As I said, traditionally they are not a group who are serviced in any particular way. The message we are getting is that people would like to think that they could access services, dip in and dip out of services at various crisis times in their life where a little bit of something could be a big help. I guess an example of that might be for someone with the late effects of polio, when that has kicked in and they are having issues with voice and swallowing and all that other stuff. Maybe some intervention around speech therapy and things like that might be of some assistance at that stage. So that is one thing.

The other message we are getting very loud and clear is about the attendant care program, which is one service that is available through ADHC for people with a physical disability. I need to say that for people who are lucky enough to be receiving that service—not the lady I spoke about before who was told it would take two years before she could get it and they would not put her on the waiting list because she was going to die before then—but if you can actually get that service it can make a real difference to a person with a physical disability because potentially it means you can go to work, you can live a good life, have a reasonable relationship with your partner if you have one but you can get out in the community, you can do things. You can be an ordinary person living an ordinary life within the community. That would appear to be what ADHC in a lot of its rhetoric aims to achieve.

CHAIR: I assume the basic issue would be that no is not an answer that is acceptable.

Ms ROBINSON: No.

Ms ELIAS: Absolutely not. Again just to reiterate the points that I made on opening, we are passionate about person-centred care. It is a direction ADHC is taking. We want to see it happen and we want it to reflect every need. We want to know that a person who enters the ADHC system is able to have their needs met or at least referred if ADHC cannot meet those needs. We need to better understand people whose needs have been unmet and I think, as I suggested earlier, for wont of a better word, a risk register of people who we are turning away so that we can start to plan for the future. Who are these people who are constantly falling through the nets? I think that needs to be not just ADHC's responsibility but obviously its funded services to ensure that we are getting an accurate picture of those things.

The only thing I want to finish off with is that people want to age in place. This is an extraordinary opportunity for what you create out of this Committee to make brilliant recommendations that reflect that reality. People want to stay at home for as long as possible. ADHC is a huge stakeholder and enabler of people being able to age in place, which in fact saves the Government a great deal of money in the long run. The other thing is—and again I will need to be prompted to provide you this—we held a forum a couple of weeks ago called the Silver Century: Prospects and Problems, and one of the academics who spoke there presented in my opinion quite new data that I had not seen before. It is Professor Bob Gregory from the ANU and he presented a picture that I think might enlighten you as well. According to his data, it looks like people who go on to the age pension have actually been on a disability support pension for 10 years earlier. So we need some seamless vision around how people are migrating from one support system to another, and we need to ensure that we understand that data a lot better because not even COTA was aware of that data until that conference.

CHAIR: Can I declare you duly prompted?

Ms ELIAS: Thank you.

CHAIR: Thank you for your time and experience. It is greatly appreciated.

Ms ELIAS: Thank you for doing this inquiry.

(The witnesses withdrew)

(Luncheon adjournment)

THERESE SANDS, Executive Director, People with Disability Australia, and

DENISE BECKWITH, Acting Manager, Individual Advocacy, People with disability Australia, affirmed and examined:

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

Ms SANDS: As Executive Director of People with Disability [PWD], Australia.

Ms BECKWITH: Acting Manager, Individual Advocacy, People with Disability Australia.

CHAIR: Do you want to make an opening statement?

Ms BECKWITH: Yes, I would. Thank you for the opportunity to appear before the Committee. People with Disability Australia [PWD], as I will continue to refer to our organisation, represent the views and interests of its members, the majority whom are with disability. We also work with numerous people with disability who live in an extremely marginalised and vulnerable situation, including those people who live in licensed boarding houses or institutional environments who come under the Public Guardian or the New South Wales Trustee and Guardian. PWD is very aware of the long-standing issues and concerns for people with disability in receiving services and support in New South Wales. We have raised many of those concerns in our submissions, as well as with ADHC and its predecessors over a number of years.

We work within a human rights framework, and we have advocated for many years for the development of an international law that would provide a consistent framework for the protection and promotion of the rights of people with disability. This law, the United Nations Convention on the Rights of Persons with Disabilities [CRPD], as I will continue to refer to it, was developed over several years. PWD is proud to say it played a significant role in representing the views of people with disability in Australia, conducting two national consultations on behalf of the Australian Government of the day, participating in several of the United Nations ad hoc committee meetings in New York, and representing the views of people with disability in Australia to that committee. The Australian Government ratified the CRPD in July 2008 making a commitment to realise the rights of people with disability in Australia. This commitment extends to State and Territory governments.

This inquiry provides a timely and important opportunity for people with disability in New South Wales as it coincides with the five-year review of the 10-year plan for Disability Services Stronger Together. CRPD had not been adopted by the United Nations when Stronger Together was developed. Now that Australia has ratified CRPD this inquiry and the five-year review should use the CRPD to audit and assess the services provided and funded by ADHC as it is highly likely the legislative framework and the institutional arrangements from practises that underpin those services will not conform or will only partially conform to the CRPD. As stated in our submission we note in a number of other submissions and evidence provided by the Committee Stronger Together only provided a first long-overdue step towards reforming a disability service systems that had been neglected for many years.

Our submission recognises the investment and increases in supports provided through Stronger Together but we also strongly outline where this plan involves breaches of human rights. New South Wales has a long way to go not only in specialist disability service provision but also in service provision and legislation across government. CRPD should be the overarching framework to continue the necessary reform and paradigm shift required in realising the rights of people with disability. This will not only ensure New South Wales is in line with the CRPD but it will also result in the reinvigoration of, and recommitment to disability rights agenda across all sectors of the community which we argue has been idle or regressing for some time. Thank you for the opportunity to make this statement. We would be pleased to discuss any questions the Committee would like us to address.

The Hon. MARIE FICARRA: Thank you for addressing our inquiry. In your submission you make a strong point of praising what has been achieved thus far by Stronger Together and government funding but you go on to state that the system is still in crisis. Will you provide us, without going into too much detail, with an understanding of why you say it is in crisis? Is it unmet need numbers of people with disability that are unidentified? Is it the ageing population? Is it a combination of both?

Ms SANDS: I think there are a number of factors. We have highlighted some examples of people who perhaps are not getting their needs met or only partially met. Certainly we have identified that there is unmet need, that there is demand for services that cannot be provided, so people are on long waiting lists or are unable to obtain a service either through Ageing, Disability and Home Care or perhaps another service system, so someone who has a psychosocial disability or an intellectual disability may not be getting a service through either system. Because we are working, through our individual advocacy service, with a number of people with disability and their families, I suppose it is part of what we see every day in terms of the service system not being able to deliver what people need, so it is certainly about numbers of people not being able to get what they need and, at the global level, I would say that the ageing population will have an impact on the demand of the service system because as people age and as there are more advancements around people with disability living longer, et cetera, then of course there will be growing demand on the service system.

The Hon. MARIE FICARRA: Would you like to approximate what sort of increase in funding you believe the next round should involve?

Ms SANDS: We have not done that and we did not provide that in this submission. We found that that would be quite a difficult task. Our main aim in our submission was to talk about the significant reform or paradigm shift that might be required. We also understand that perhaps organisations like National Disability Services would be looking at calculations of figures. We would certainly say that there needs to be a significant increase in funding that would take into account some evidence around population benchmarking. We have not got that evidence at the moment in New South Wales, so there does need to be some research and figures equivalent to that, but generally speaking, if you are thinking of people with disability as about 20 per cent of the population, we need to be thinking about what amount of the budget goes towards servicing people with disability or providing services for people with disability.

Ms BECKWITH: I think it is really important to have an individual focus because people with disability have very different needs in comparison to what I would, for example, so what I would cost the Government would be different from somebody who has higher care needs, so there needs to be a focus more on individual approaches rather than a bucket of money to have a specific service provider because that specific service might not meet the individual's needs.

The Hon. MARIE FICARRA: We keep hearing that from many of the witnesses who come before the inquiry. I perhaps should have asked my next question at the beginning, but how do you get your funding from Ageing, Disability and Home Care and how big is your organisation?

Ms SANDS: We receive funding from Ageing, Disability and Home Care to play a peak or representative role for people with disability. We also receive Commonwealth Government funding to provide individual advocacy services in New South Wales and Queensland and we receive further Commonwealth funding to run two national hotline services, the national abuse and neglect hotline and the Complaints Resolution and Referral Service, which takes complaints around disability employment services and advocacy services. Our funding through Ageing, Disability and Home Care is probably a smaller component of our funding. We also receive project funding through Ageing, Disability and Home Care for the boarding house project specifically, which is providing individual advocacy support to residents of licensed boarding houses in New South Wales.

The Hon. MARIE FICARRA: How is the latter aspect of your advocacy, the number of boarding house dwellings that exist and those people with disability living within that type of accommodation, generally faring?

Ms BECKWITH: At the moment there is quite a demand on our work in that area. We are actually supporting a number of residents through closure of licensed boarding houses, so we have to support them to find alternate housing, and we cover the entire State, so we support residents in the northern region of New South Wales, Millthorpe, Wallerawang, Newcastle, the Hunter region, and the inner west as well, so there is a team of people that work specifically with all residences. We have had difficulty actually getting into some of the premises because the owners do not like us in there, but Ageing, Disability and Home Care fund us to provide support, so we do that and we go there regardless of having difficulty getting in because we know that those people are the most vulnerable and marginalised people.

Ms SANDS: Overall, how they are faring, because the boarding house sector is not covered by the Disability Services Standards or the Disability Services Act, it is governed by the Youth and Community

Services Act, which is a very old Act and, as you are probably aware, there has been a process of reform, but it has been stagnating over the last 10 years. We are very concerned that that Act has not been modernised to concentrate on the rights of residents, so I suppose a lot of our work with residents is looking at their basic rights to be able to have choice about what they do and where they go. There are incidences of people in boarding houses who are forced to take the annual holiday that all residents take, where there is a lot of over-medication or medication distributed inappropriately; where the whole of their disability pension or 80 per cent of it may be going to support their lodgings and food with very little left over; there are a lot of punitive measures to perhaps control what is called challenging behaviour which might be taking cigarettes from people or only distributing them at certain times—

Ms BECKWITH: Only distributing two a day.

Ms SANDS: There is a whole range of abuse and neglect issues, and we have seen recently a number of deaths in boarding houses, which certainly on the face of it look like neglect—on two occasions people who had died not being found for, say, two to three days.

The Hon. MARIE FICARRA: Why do you think governments are so slow to improve the regulation of this sector of housing? Is it a fear that the owners of those premises will say it is not profitable and they will redevelop it and turn it into commercial or modern residential?

Ms SANDS: I think that is part of it. If a person with disability is supported in a boarding house it means that is the lowest level before homelessness, if you like. So if they are going to modernise the Act and have enforceable regulations covering boarding house proprietors there would need to be some investment in boarding houses to bring them up to standard in policies, procedures and, I suppose, conditions and reporting that proprietors would have to meet. It is highly likely that a number of boarding house proprietors may choose in that case not to continue their licence. At the moment if a boarding house is closed it is very difficult to relocate residents because there is no appropriate supported accommodation. Residents generally may end up going into nursing homes or other supposedly temporary accommodation, but they end up staying in that accommodation because there is nowhere else to place them. They end up in the temporary accommodation for long periods of time.

Ms BECKWITH: There was a closure recently and people have ended up in what we would consider an institutional setting as a transitional model but they are staying there because there are no other options available to them by way of accommodation and support services that those individuals need.

The Hon. MARIE FICARRA: How much institutional accommodation care is still out there and what is your opinion of it? I guess the standard varies. Is it a necessary evil or what are we to do with large institutional residential placements?

Ms SANDS: We have a very strong view that institutional accommodation should be closed. That was a commitment by the Government.

Dr JOHN KAYE: Can you define what you mean by institutional accommodation?

Ms SANDS: I mean accommodation that congregates, segregates and isolates people with disability. That may be a large residential setting such as Peat Island or Lachlan or it could mean a nursing home where people with a disability are living. It could mean a boarding house or it could be temporary forms of accommodation that ADHC is now promoting, such as cluster housing, villas or residential centres that are called a new name but in fact are simulations of larger institutions that have historically existed, because they still congregate, segregate and isolate people with disability.

The Hon. MARIE FICARRA: Is there a proportion of people with disabilities who might wish to be in, not an old, large institution, but a cluster group and surrounded by others with disability and perhaps mainstream people?

Ms BECKWITH: There may well be, but people with disability in those setting are not given choices. So, if you do not know what is available out there how are you going to truly make decisions about what you want when you have lived in only one setting for a really long time?

The Hon. MARIE FICARRA: So basically there should be far more options and we should get away from that old, large institutionalised system of accommodation?

Ms SANDS: Absolutely. In 1998 the New South Wales Government made a commitment to closure. At that time they obviously were happy to accept the evidence, which was national and international, that those forms of accommodation were not appropriate for people with disability, and therefore they needed to close. As we have seen with the recent release of the New South Wales Ombudsman's report, there were 2,000 such people at that time and there are still 1,600 people in large residential centres. Obviously that report concentrated on large residential centres, but we have not come very far in shifting to inclusive forms of accommodation where people genuinely live in the community and are able to be included in a different way than if they are living with their peers in an isolated environment. That is quite different from being able to live in the community. We have a regular e-bulletin and some months ago we released an e-bulletin that gave an overview of the situation in New South Wales of all the ADHC-provided and funded types of institutional accommodation. I have brought a copy today if the Committee would like to see it. It was produced in February 2009, so it is about 18 months out of date, but it provides an overview of the various accommodation options and some of our arguments about why we feel they are not appropriate for people with disability.

CHAIR: The document can be tendered.

Dr JOHN KAYE: I would like to follow up some of the points you raised, which I think are very interesting. Are the 1,600 who are in institutional care at the moment in New South Wales in the older-style large organisations or does it include the new villa-style accommodation?

Ms BECKWITH: That would include the villa situation as far as I am aware because they are talking about the redevelopment of Lachlan, Peat Island and Grosvenor.

Dr JOHN KAYE: Is your key concern the aggregation of people with disabilities and putting lots of them in one location? Is that where your concern comes from?

Ms SANDS: Our concern is based on the objects of the Disability Services Act as well as the Convention on the Rights of Persons with Disabilities, which outlines that people with disability should be able to be included in the community and live independently and have the same and equal choices as other people. People with disability have historically been congregated together and isolated in that way because that is the only way they can receive a service. It is not a choice being made; it is actually to receive a service through the service system.

Dr JOHN KAYE: You said the evidence said it was not appropriate. Did the evidence you referred to, which is from a decade or so ago, talk about the inappropriateness being because of isolation from the mainstream community?

Ms SANDS: It talks about that. There is also contemporary evidence now as well. There is evidence to show that that isolation, congregation and segregation for the purposes of providing a service do not allow a person to develop skills to their maximum ability. In fact they may develop behaviours that are quite negative but which are called challenging behaviour. Those behaviours change when they are in more appropriate settings and the capacity of people and their ability to function changes when they are in different settings. There is a lot of evidence about that. We have members who have grown up in institutions who tell us the same story.

Dr JOHN KAYE: Who have then subsequently moved out of institutions?

Ms SANDS: Yes, and are living in community settings, perhaps independently in houses with supports around them that they need, but who say it has taken them a long time to learn a whole range of social skills, because they never learnt them, and how to interact and be able to go shopping independently or cook. They have never had to do those things. Even now people in large residential settings often have frozen meals and TV dinners and things like that. Our members also tell us that shifting to the community had a significant impact on their skill development, on their ability to be able to have choice, and on being able to do things that they were told they would never be able to do because they were considered deficient in certain respects. In fact, our current president grew up in an institution and was told, when she left that institution 15 years ago, that she would not last a week in the community. But she has been living in the community with supports around her, and leading an independent life.

Dr JOHN KAYE: You suggest that the Convention on the Rights of Persons with Disabilities [CRPD] provides, or should provide, an overarching framework for Stronger Together 2.

Ms SANDS: Yes.

Dr JOHN KAYE: You also say that it should be the basis for writing policy in this area. Can you expand on what that means in practical ways? As an example, I am taking you there from the issue of the institutions versus supported accommodation. Do you have a view on the way in which the CRPD practically translates to what we should be doing?

Ms BECKWITH: What I think that brings us to is that ADHC, for example, funds supported accommodation, or group homes as they are referred to, but at the moment they are only open to people with intellectual disability, if you want ADHC-directed services. Also you have people who have complex needs and who may not have an intellectual disability, but who need supported accommodation and need that support. But that is not available to them under the interpretation that ADHC uses.

We have had contact with a client who has HIV and needs support around his personal care needs, but is not able to get that. He is not eligible for an ADHC group home because he does not have an intellectual disability. If the CRPD was attributed to, followed and adhered to, it would not have restrictions on the kind of disability that a person has.

Ms SANDS: I think that is a practical example of the issue in which the service system and policy development have to change—looking at people in terms of a diagnosis and not looking at them in terms of what the outcome needs to be when a human right is realised. Take for example living independently in the community: you have to look at all the barriers that are stopping that person, regardless of their diagnosis, from achieving that. Given the way the convention is written, policy development needs to look at what does the right say? What do I need it to achieve? How will the policy flow from that? How will we get to that end-point where the outcome or the human right of a person is realised?

I guess what we would say is that there would not be a focus on redevelopment of institutions, if that was the case and if that was the framework because it would be clear that the principles outlined in the convention would say that that is not appropriate. We would not be having a discussion about redevelopments. We might be having a discussion about how we reconfigure the service system so that people do not have to fit into boxes and be captive to what the service system expects of the person. We might be discussing that people are directing and pulling in supports that they need around them, and they have control over that.

Dr JOHN KAYE: Ms Sands, when you spoke about moving away from the diagnosis model, I thought what you were going to talk about their was moving away from the diagnosis model towards a functional capacity model whereby you assess each individual's functional abilities and you work with those. I was quite surprised to hear you go from moving away from a diagnosis model to moving towards what might have interpreted as a deficit model—what people need to reach a certain standard. Was that intentional?

Ms SANDS: No, that is not what I mean. Actually, it is not what I mean. We have a recommendation in the submission and that assessments need to look at consistency and something that allows a person with disability not only to look at their functional ability in terms of what they are able to do, but also look at the social and environmental factors that impact on a person so that they cannot achieve inclusion.

By that I mean that we have referenced the World Health Organization International classification for functioning and we are doing some work on that at the moment for the Productivity Commission inquiry around assessment and eligibility. We believe that if you look at the person with disability as an individual, irrespective of the diagnosis, you need to assess what they will need to obtain meaningful employment, housing and education, et cetera. Some of those things will involve attendant care home support, et cetera, but they may also involve an accessible transport system and accessible workplaces.

There is a whole range of factors impeding a person that have nothing to do with individual impairment. They have everything to do with the changes required in the broader environment, if you like. Assessments need to be much broader than just looking at whether a person requires medication, home care supports and behaviour management. That is really a focus just on one aspect of an individual. It is not the broader component of a whole-of-life ability to move around and be part of a community.

The Hon. HELEN WESTWOOD: Does People With Disability believe that there is a place for supported accommodation, or do you think the optimum is that people should be able to remain living in their own home with the services they need?

Ms SANDS: Denise will probably have something to say on this. We are not necessarily saying that forms of supported accommodation should be eliminated, if you like, but there needs to be a different emphasis on how accommodation is provided. For example, even if we are not talking about large residential centres and we are talking about group homes, often there still is no choice in group homes about whom a person lives with. If there is resident-to-resident abuse, often it is the person abused has to move, not the perpetrator. If someone is under behaviour management, the whole house is influenced by that. If they are not allowed to watch certain TV programs, for example, no-one in the house is allowed to do that.

It is about how the person has control over their life and how they are in control of the housing and the circumstances they have, and the support around them. But having said that I need to say that that housing support needs to be the same choice as everyone else would have—whether that is an apartment, a unit, perhaps a house in the suburbs, or however that is configured.

Ms BECKWITH: At the moment housing and the need for accommodation in New South Wales is very crisis-driven. People have to reach a point of homelessness to be considered for a place in a group home or supported accommodation placement as it exists. Because they are homeless, they are actually encouraged to take whatever option might be available at the time. Yes, it is considered against compatibility and supposed challenging behaviours rather than the individual and what their family needs are and what their cultural needs are and things like that.

I could give you an example. I supported a young man who had intellectual disability and autism. His mum was really, really supportive. She lived in western Sydney and wanted to remain involved in his life in an ongoing basis. Because the regional offices of ADHC are so broad—for example, North goes from the lower Blue Mountains through the western suburbs of Sydney and to the Northern Beaches—they were offered a group home placement in the Northern Beaches. But because of the socioeconomic circumstances of this family, that was not a viable option for them to maintain their family contact.

Fortunately for that family they had advocacy assistance to say no, this is not a suitable option, but I could see that if people were not supported by advocacy and not competent to say, no, this is not a good option and it is not sensible, in conduct with the disability service standards which encourages maintaining family relationships and stuff like that, then they would take it because they are so crisis driven and they do not want their homeless child, who might be abandoned in a respite service because they cannot manage in the family environment any more.

CHAIR: The choice you cannot refuse.

Ms BECKWITH: Yes, that is it.

The Hon. HELEN WESTWOOD: Can you point us to an optimum model where support accommodation is appropriate? Is there another jurisdiction where you have seen accommodation services, support accommodation and people remaining living at home with support that you think does it well? Not only in Australia. I mean overseas as well. Do you have any knowledge?

Ms SANDS: There have been different approaches. There have been different approaches within Australia in different jurisdictions around supporting people to live in their own home or to live in apartments with a person of their choice, not necessarily a person with disability either. There are also examples in the UK and in British Columbia in Canada—I suppose it is more a community development aspect—where families have supported their child to develop relationships with other people in the community who then may be keen to live with that person and they may live in a flat or an apartment with supports around them, but they are in an environment where they may have transport difficulty, but they may have other friends in the community and they are not segregated, if you like, or simply in an environment because they have a disability.

So they have a choice that is equivalent to other people in making choices about where they live. Families did that initially in British Columbia in Canada because the service system was not responding. So they came together to try and find a way to support their adult children to have the supports they needed but to live in the community, because they felt that that was what they wanted for their sons and daughters and not to have the limited options which the service system was only providing at the time. There is probably a whole range of literature as well and research done around various models. I would have to refer those to you. I am unable to do that now.

The Hon. HELEN WESTWOOD: No, that is fine. If you think of something if you are able to refer to it, that would be good. The example that you gave us earlier, Denise, that may be the one that you are referring to in your submission or one of the examples, that people with disability and their family who move from one regional area to another are unable to receive the same services that they had originally, are there other examples of that and how do you think that may be overcome?

Ms BECKWITH: I had an example of that with a client of mine who moved from Taree to western Sydney. In Taree they had the supports that they needed, like behaviour intervention support, case management support, an appropriate house and they moved to western Sydney and they were put on a waiting list for nine months before they came in contact with us and they could not get the same service that they had in Taree, but they still needed it. Their disability needs did not change because they moved from Taree to western Sydney. They moved to western Sydney to be closer to family. So they were on a waiting list for nine months, and we provided advocacy assistance around getting the appropriate supports in place, but they waited that time and if they did not have advocacy assistance, they could have been waiting for support for a very long time. You cannot have that. Your disabilities needs do not disappear because you move from one area to another.

The Hon. HELEN WESTWOOD: Is that because the services do not exist in western Sydney or because there is a great demand and it is not being able to meet the demand?

Ms BECKWITH: I think it is the demand, but I also think it is because in regional towns you get to know people more locally and you have got that local approach, people are a bit more responsive, whereas in western Sydney because there is so much demand you cannot be as flexible as you can in a smaller area. But in saying that, in regional New South Wales you cannot get some services either because the services are not there or because they cannot get the people. So it is a double edged sword.

The Hon. GREG DONNELLY: Thank you for coming along today and giving us some additional evidence to the material you provided in your submission. I would just like to return back to the issue of waiting lists and how waiting lists as a way of identifying unmet need can be improved. A number of witnesses have explained that there is not particularly good information held by the Government about waiting lists in terms of people with various disabilities. It has come out in their evidence that they, as organisations, often maintain their own form of waiting lists which they use internally to work out how they are going to plan and allocate resources, et cetera.

What are your thoughts about this whole issue of very significantly trying to upgrade and improve the waiting list information about people with disability in New South Wales, do you think that is a good thing? If you think it is a good thing, how do you think we could set about to do at that? What do you think would be a sensible way of initiating that idea of getting a consistent waiting list being maintained by the various NGOs and other related organisations?

Ms BECKWITH: In regards to accommodation, we are quite often told that there is no waiting list for accommodation, that they do not keep that, they only have meetings when there are regional vacancy committee meetings. So we are told that there is nothing and no-one can put their name forward and forward plan, which does concern a lot of families, particularly as they are ageing because they want to put things in place for their children, to know that they are safe and that they are well set up and established to meet their individual needs. That is one really big concern that we have: You cannot forward plan, which is one of the greatest things I get called about all the time, because I am told, "I have been told to make my child homeless in order to get supported accommodation because I am getting older, I can't have them in the family home anymore."

The Hon. GREG DONNELLY: Can I interrupt what you are saying. Could you just elaborate what on what you have just said, they been told what?

Ms BECKWITH: They have been told to make their child homeless.

The Hon. GREG DONNELLY: Who has told them that, as you understand it?

Ms BECKWITH: The families that have done it themselves. They may have had a block of respite and because they are in a critical situation they are so exhausted, so worn out, that at the end of the respite period they have rung up and said, "We can't do that. We can't look after our child any more", therefore rendering them homeless.

The Hon. GREG DONNELLY: So they have come to the end of their tether, they have completely sort of had it.

Ms BECKWITH: Yes. There is no waiting list so you cannot build on a waiting list for accommodation placement because the demand for accommodation in whatever form it comes in is so high that when you actually say, "I am reaching the point I can't do this any more". It is sad to hear that from families. I have been working for People with Disability Australia for eight years and I have heard that story so many times, and you should not have to be in that situation. I have heard other stories where children with early intervention support needs, so you want to avoid your child needing long-term support, are waiting two years for speech pathology or physio because the demand is so high, but yet you want to reduce the amount of support they need in the long term. If you cannot get early intervention when it is needed, when they are young and can develop skills, what is the point of it?

The Hon. GREG DONNELLY: With your work with other non-government organisations—you have obviously had that role for some years now, which is very good; you are doing a great job—you talk to different people in other non-government organisations. Do they talk about the waiting list issue and how this is a matter for them?

Ms BECKWITH: Case Management Services call us a lot and actually want advocacy support when a person needs case management support but they are at a critical point themselves. They are full. Case management is about networking a whole range of services. We are funded primarily as an issue-based advocacy service so we cannot take on that case management role because it is not what we are funded to do. We are actually getting referrals from Case Management Services because their demand is so high for actual networking support and what the person needs is more networking support than an individual issue because they have multiple issues and multiple skill development that they need to have.

Ms SANDS: Further to the waiting list issue, I do not think there is any consistency in ADHC around waiting lists. There is no waiting list for home care and so a similar thing applies with people—they just assume because they are told there is no waiting list—

The Hon. GREG DONNELLY: Other witnesses have essentially said the same thing.

Ms SANDS: So it is not consistent across the various service systems. I think the service system needs to be moving more towards an entitlement-based system so that there are no waiting lists. If you are eligible you should get the service. But that is a long way down the—

CHAIR: You describe it as an entitlement-based system.

Ms SANDS: Yes, and that is in line with a rights-based approach. If you are entitled to have a service or supports around you so you can live your life, get out of bed in the morning and not have to wait until 10 o'clock to do that but you might want to get out at six, and you might want to be able to control if you can go out on a Saturday night and when you can be put back to bed, et cetera, then you need to have the flexibility to do that but you also need to have that service, you are entitled to it. It should be seen as an entitlement to live the life that you are entitled to live so it is not a system where you are on a waiting list because if you are lucky you might get a service and therefore it is a bit more like a welfare charity type of system. There needs to be more of a view around entitlement for people with disability to live the life that everyone else in the community can live.

CHAIR: So that there is no answer no, there is no service, and there is no waiting list, that when you need a service you are provided with a tailored service.

Ms SANDS: If you are eligible for that, yes. If you are in a more individualised approach you can then choose the service you need at the time, the supports you need, and bring that around, bring that to you as you need and decide.

CHAIR: As a player, as people with experience in the area, can you give us an educated guesstimate as to the unmet need in terms of percentages? You have been talking about these people who are leaving their loved ones in respite care and saying, "I can no longer look after them". You are talking about other examples of unmet need. What is your guesstimate in terms of percentages? Are we talking 20 per cent?

Ms BECKWITH: It is hard to put a number on it because the different regions count it differently.

CHAIR: No, your informed, educated opinion.

Ms BECKWITH: We actually have not done that. We have never actually said to someone that you can do this in order to get supported accommodation.

CHAIR: I am not suggesting that. What is your guesstimate as to the unmet need in terms of percentages?

Ms SANDS: I am not sure that we can provide that at this point.

The Hon. GREG DONNELLY: You can take it on notice perhaps.

Ms SANDS: We could take it on notice. I think there are a number of factors though. The reason why it is hard to look at is because there are a number of people who spend a lot of time trying to be independent and not need a service because they are never eligible. So if you factor in those people who are perhaps not getting a service at all but would benefit from one, that is one consideration. Then you have situations where you have a large percentage of Aboriginal people with disability, for example, who do not even know a service system exists. So there are quite a number of factors involved in that.

CHAIR: First of all, we have to define what we mean by "unmet need". We are having difficulty doing that. We are having enough difficulty defining an institution. Perhaps we should be asking you in terms of silos—if we can go to that issue quickly—

The Hon. GREG DONNELLY: I have more questions as well.

CHAIR: Sure. In terms of the silos, can you give us your thoughts on the different types of disabilities that cause silos, the issue of geography, regions, and going from one region to another region there are problems with the services following you or not following you, and the State and Federal silos that cause difficulties so that you may be able to get home care but you cannot get attendant care if you have home care and all those issues that are causing problems with unmet need? I know that is a big question and I know we have to exhaust the Hon. Greg Donnelly's questions. Perhaps you might take it on notice.

Ms SANDS: Yes, okay, thank you.

The Hon. GREG DONNELLY: Going back to the issue of unmet need, you have already made comments about the indigenous communities. In terms of the general population in New South Wales, you obviously have people with disability coming into the non-government organisations seeking advice, supports, et cetera. Do you have a view about the numbers or potential numbers of people with disability who are not connected at all or in any significant way and in some sense are just trying to get by as best they can because, for whatever reason, they do not feel confident enough to try to make the approach or perhaps they may have had a bad experience in the past or other matters? In other words, is there a view that there are quite a few people with disability who are in a sense disconnected with the sort of avenues that are available that otherwise provide them with assistance and support?

Ms SANDS: I am not sure if I can give numbers but we constantly hear that people who are classified as having low to moderate needs are usually people with low to moderate intellectual disability who do not need intensive supports but do need some living skills support, maybe some social activity support. They are receiving nothing and are never provided with any service. They are not seen as being in a priority group for ADHC services. Often they have support through their membership of organisations like PWD, for example, and peer support but they do not actually receive the services they need. I know of cases where that has been the case for a number of years and where that person's situation might change to the point where they might be, say, at risk of homelessness then they hit the high priority area and they will get the ADHC service, but only if they are lucky enough to have an advocate to support them to do that because they are not actually used to asking for the service because they have not received them before.

It is usually people who are classified as having low support needs that generally do not get the service but could benefit from it. Often people with more complex needs—say they have might have HIV and an intellectual disability, they might also have a psycho-social disability so there are quite a few different avenues and services in different service systems—they are being told by one service sector that they are not eligible there, they are not eligible in the mental health system, they are not eligible in, say, the HIV-Aids system and they fall through the gap and do not have any service system. Those people will often rely on informal support structures through families and friends and yet, quite clearly, need a service.

I understand the Aboriginal Disability Network will be appearing at the hearing at the end of September. We are co-located with the Aboriginal Disability Network and often take Aboriginal people with disability who need individual advocacy are often referred to us from the Aboriginal Disability Network. The Aboriginal Disability Network constantly tell us on its visits to communities that it is just very common to meet numerous families and people with disability who are not even aware of what services they are eligible for, and what the service system is. That could be because of attitudes towards say, government or non-government services or inappropriate services, they are not cultural appropriate, et cetera. So there are people doing without services in quite high numbers in those communities. It is very hard to estimate.

The Hon. GREG DONNELLY: Of course, but you say it is not insubstantial?

Ms SANDS: That is right.

CHAIR: Your evidence has been very helpful for the Committee. The Committee may need to send you some questions on notice in the next couple of days.

(The witnesses withdrew)

JO-ANNE MICHELLE HEWITT, Chairperson, Futures Alliance, and Director, Uniting Care Disability, affirmed and examined:

PAUL MICHAEL SADLER, Chief Executive Officer, Presbyterian Aged Care New South Wales and the Australian Capital Territory, and a member of Futures Alliance, and

MICHAEL JOHN BLASZCZYK, General Manager, McCall Gardens Community Ltd, and member of Futures Alliance, sworn and examined:

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

Ms HEWITT: I represent the Futures Alliance and Uniting Care Disability.

Mr BLASZCZYK: I represent McCall Gardens Community Ltd and as a member of Futures Alliance.

Mr SADLER: I represent Presbyterian Aged Care and the Futures Alliance.

CHAIR: Do you want to make an opening statement?

Ms HEWITT: Certainly. We commend the inquiry into ADHC services and thank you for the opportunity to appear today. We are appearing on behalf of the Futures Alliance. The Futures Alliance was formed in recognition that current policy and practise in both the disability and the ageing arenas falls short of the required response to support people with a lifelong disability as they age. We are a cooperative of community representatives from disability and aged care providers in New South Wales and include representation from consumers, academics and peak bodies. Our purpose is to remove boundaries and maximise community resources to deliver improved options for people with a disability who are ageing. The Futures Alliance has been formed and has grown via a network of professional relationships with a shared vision of influencing policy pertaining to people with a disability who are ageing, and ultimately improving outcomes for this group of people.

The submission that we have made to this inquiry is a document that we have dubbed the blueprint on ageing with a disability. We have spent the past 12 to 18 months as a group discussing some of the policy and practise gaps that we currently see and consulting with people with disabilities and their families around some of the issues that they are facing as they age.

We have put together basically what we think has addressed some of those policy gaps. We are very hopeful that the recent changes under the Council of Australian Governments' National Health and Hospitals Network Agreement makes the funding mechanisms clearer. However, we are concerned that there still has not been articulated how those policy mechanisms are going to come together to ensure that people with a disability who are ageing still will not fall through the cracks.

We have called for a number of things to happen for people with a disability who are ageing. We know that people with a disability who are ageing want genuine consultation about their aged care needs and how they will be met. We support the notion of self-directed individualised funding with the flexibility to meet complex needs. We call for recognition as a special needs group within the aged care funding and legislative framework, so like other special needs groups who are able to access aged care systems much earlier, we recognise that statistics show that people with a disability are ageing earlier and have much more complex needs as they age and so believe that one of the mechanisms may be for people with disability to be considered as a special needs group under the aged care funding and therefore get some special consideration, both early entry as well as some policy and funding directed towards them.

We recognise that the current aged care assessments are not appropriate for people with a disability and do not take into consideration their complex needs, so that is another area that we believe needs to be addressed. We would like to see access to all Commonwealth aged care programs, including packaged and flexible care options, and I guess that is one of the areas where we see people falling through the gaps, that often people will have some service and some funding via the State, which tends to not change as they get older, and then when their needs become more complex and they require more specialised services they are not eligible unless they relinquish their disability funding. One of the mechanisms that we see would be appropriate is for those two buckets of funding to work hand in hand and for those specialist resources to work alongside the disability services so that people get the resources that they require.

CHAIR: It seems fairly fundamental.

Ms HEWITT: Yes, absolutely. That requires flexibility and collaboration between all levels of government. The Chair spoke before about silos, and this is very much what we see in this area, that there are silos particularly around the Federal and State split and there are many people who are falling through the cracks of those silos. We would like to see funded partnerships between disability and aged care providers to allow collaboration and cross-sector development and professional development of the workforce in both the aged care and disability sectors, and consistency between the disability and the aged care standards to ensure human rights and accountability. I am aware that even within the disability sector there is a variety of disability standards that are not necessarily consistent. I guess these are some of the things that we have identified. We are not making criticism of Ageing, Disability and Home Care services as such; what we are saying is that there is often a policy gap between the Federal and State departments, so once you get into one system it is impossible to get into the other, and the two do not talk to each other, so that is really what we are concerned about.

CHAIR: Are you saying they also have different definitions of standards?

Ms HEWITT: Yes, the standards are different. In essence, some of them might say the same thing, but because they are worded differently there are different connotations to each of them, so that is a difficulty in itself.

Dr JOHN KAYE: You show some degree of optimism about the Council of Australian Governments' National Health and Hospitals Network Agreement.

Ms HEWITT: As a funding mechanism.

Dr JOHN KAYE: You made some comments about that. Would you like to elaborate further, particularly on what you think are the practical implications as to how this is going to run?

Mr SADLER: In broad terms, the Council of Australian Governments' agreement included a decision to identify the funding for people over the age of 65 as aged care funding, and therefore it will be administered and funded through the Federal level, and anybody who is under the age of 65 is going to be funded and administered through the State level. Clearly one of our concerns about this particular group of people is that they are getting to the point where they cross that boundary, so the key question is how that will work in practice. In the National Health and Hospitals Network Agreement the statement that was made by all the premiers and the Prime Minister at the time was that the way it will work is that it will effectively be a funding transfer and that the services will remain the same, so if you are a disability service provider who is providing to an ageing person with disability who gets to the magic age of 65, as you read the agreement, it looks like they can continue to receive the service from the disability service provider as the person gets to 66, 67, and there will be almost like a book entry transfer of the funding responsibility between the two levels of government. I guess at one level that is fine. The concern that we have from a practical point of view is that we know at the moment—and Jo-Anne talked about this—there are some instances where you are denied access to the Commonwealth aged care programs because you are already, for example, living in a group home, so some of those issues are not addressed at all in the commentary in the agreement, which is largely around the funding responsibilities.

Dr JOHN KAYE: Does the quantum of funding change?

Mr SADLER: Not at that point from what we can see, but there is a level of detail in the way this will roll out, which is yet to be clarified. In the first instance, the primary focus of the agreement was the splitting of the Home and Community Care Program, but clearly captured to some extent is the broad disability services and Commonwealth aged care programs. For example, my organisation, Presbyterian Aged Care, sees people who have dementia who are younger than 65. It is relatively rare, but there are a number of people who have younger onset dementia. It appears on the reading of the agreement that at the moment those people will be reclassified as younger people and therefore the funding responsibility for those people will fall to the State Government. At the moment their needs are primarily funded by the Commonwealth aged care programs. So there are some interesting implications of the agreement and I do not know that we know exactly how they are going to pan out in practice.

CHAIR: Are you saying you have to fall into one or the other? Would there not be the flexibility of a mix?

Mr SADLER: I think that is a very good question and I guess from our point of view one of the key messages we wanted to get over to the Committee today was that for this particular group of people who sit across that dividing range it is going to be really important that the Federal and State systems, the aged care and disability service systems, can actually work together. They have not done a particularly brilliant job of doing that to date. The fact that we now have a funding level agreement between Federal and State governments is a good thing and probably a step forward because it clarifies funding responsibilities, but that does not in itself mean that the services or any additional resources have been provided to address the service gaps that currently exist.

CHAIR: It seems fairly fundamental. There will be a requirement of many individuals to have services, some delivered by the State and some delivered by the Federal Government, and at this stage Home Care and Attendant Care, for instance, are exclusive—you cannot have both.

Mr SADLER: Yes.

Ms HEWITT: And really this is an emerging issue in that, in the past, people with particular disabilities would often not live to be 65. Statistics are showing us that increasingly people are living well past 65 and in fact are living to regular ages. The combination of increased medical science and people living in the community and having better health outcomes by virtue of living in the community means they are living to an older age. This is not something that the disabilities system has necessarily confronted in the past. We have known about it for a while but we have not really done too much about it.

The Hon. HELEN WESTWOOD: Have you been involved in the Stronger Together 2 consultations?

Ms HEWITT: Not at this point, no.

The Hon. HELEN WESTWOOD: You have not been involved or you have not been aware of them?

Ms HEWITT: We were not specifically invited.

Mr BLASZCZYK: I was not invited.

The Hon. HELEN WESTWOOD: Are you aware whether the issue of people with a disability ageing and therefore having different needs is being considered as part of the Stronger Together phase 2 review?

Ms HEWITT: I am not sure in terms of the Stronger Together review. We have written to ADHC on a couple of occasions and wrote to the then Minister, Paul Lynch, and a senior officer from ADHC attended one of our meetings and was very interested in the issue. Then there was a bit of a restructure and we had a new Minister. We have recently been contacted by another senior officer from ADHC saying they are currently doing an ageing-in-place project, which is specifically around their large residential centres and group homes, and they have said they will come and talk to us. That is the sum total of our engagement on this particular issue with ADHC at this point.

Mr BLASZCZYK: There is a large residential centre project happening and ADHC have been working on that for six months now, within the non-government sector, and 14 NGOs have been involved. That is a submission specifically for Stronger Together 2 funding. That population includes quite a number of older people with disabilities, so they are looking at the best kind of accommodation support arrangements for those within the large residential centres.

The Hon. HELEN WESTWOOD: I was not here at the beginning when you made an opening statement so I apologise if you have already provided this information. Are you aware of the capacity of aged care services to accommodate the needs of older people with disabilities and are they planning for it? Do you think aged care services, whether they be accommodation services or support services, are adequately prepared for a population of people with disability who are ageing?

Mr BLASZCZYK: The Futures Alliance were set up to get the dialogue happening and one of the things that came out in the first few meetings was the difference in approach, so aged care would be working towards end of life approaches and disability would be working towards a developmental approach. I think we have come to some understanding now that we can meld the two to make sure those needs are met.

Mr SADLER: I agree with Mike. I think the aged care sector has been, like Jo-Anne's comments about the disability sector, relatively unaware of this looming new group of potential clients of our services until the last few years. Some work has been done in New South Wales by the Aged and Community Services Association, then ACROD, now National Disability Services, and the Council of Social Service of New South Wales [NCOSS]. Consultations were held including the aged care and disability sectors about five years ago, so that was the first raising of the issue in the broader sector. About the same time, the Federal Government put out what it called innovative pool funding, which looked at the availability of Community Aged Care Packages [CACP] to people who were ageing with a disability. Mike and Jo-Anne's organisations were both involved in some of that project, but it was very much a one-off pilot project from the point of view of the Federal Government. It has not been extended to become an ongoing part of the Commonwealth's aged care programs at this point.

Ms HEWITT: That project basically provided people who were living in group homes with support from an aged care provider, mostly with CACP and Extended Aged Care at Home [EACH] packages, so that they could remain in their accommodation and age in place, but were provided with that specialist level of support. Often it involved training the disability staff to better identify as well as address some of those ageing needs. Mike can probably give examples of some great outcomes from that.

Mr BLASZCZYK: Brilliant outcomes in comparison with prior to the program being introduced to McCall Gardens. We were having to pepperpot people around nursing homes and in our heart of hearts we knew their disability needs were not being met. With the program providing that expert aged care dealing with the aged care issues—it provides on average an extra 1.5 hours of support per person per day, which is not a lot—it has meant we have not had to have any admissions to aged care since the program has been in place. It has meant that the staff have developed amazing competencies and skills with palliative care and end-of-life care, so people do not have to leave necessarily to go to nursing homes or hospital to die. We are thrilled with that result. I think the overall review across the country was similarly positive.

Ms HEWITT: We need to be really clear that we are not calling for people with a disability to have early entry into residential aged care. We do not believe that is either what people want or what will meet their needs. We are really calling for access to specialised allied geriatric services, for example specialist advice and training for disability services, and some extra funding. As Mike said, an extra 1.5 hours a week is not a lot of extra funding but it made the world of difference to a group of people who had ageing needs and whose disability needs were changing. We talk to disability organisations all the time who are caring for people who are ageing and who say, "We don't really know what to do. We're funded to provide X for these people." Mostly they are funded not to open during the day and suddenly they have people who are unable to go to work or their day program. They may have issues such as incontinence, increased falls, and even dementia, and their disability services are not geared to cope with that. At the same time it is often a place where people have spent many years and their family and social networks are centred around it. The last thing we want to do is see them leave that environment.

The Hon. HELEN WESTWOOD: One of the groups we talked about with representatives from People with Disability and the Council on the Ageing earlier today are those with a disability who end up being cared for by someone who is ageing, to the point where they may not be able to care for that person anymore. Is that another group you see as an emerging group of need?

Ms HEWITT: Absolutely, for sure. Often those people are ageing at the same time as their ageing carer. It might be somebody who is in their 50s or 60s and is developing those signs. As I said, people with disability do tend to age earlier. They might be living at home with mum who is in her 80s or even 90s and is suddenly faced with the fact the person they are caring for is losing their skills at the same time as they are losing their capacity to care for them. It is a huge emerging issue.

The Hon. GREG DONNELLY: Thank you for attending. I have had an opportunity to have a look at your submission. Is there anything in particular in your submission that you would like to take the opportunity to elucidate, now that you are before us, or specifically draw out a little bit and put an emphasis to? That is a general question.

Ms HEWITT: Yes. Apart from the things we already have mentioned, the things that we were particularly interested to mention is the issue of people who currently receive a disability service not having access to specialised aged care services. One of the things that I am not sure we mention in the policy paper, but which is a real issue as well, is that currently ADHC has a program that is specifically designed to get young people out of residential aged care. However, there is not the same level of resources in preventing other people from entering residential aged care prematurely. There is a bit of an imbalance there.

Mr BLASZCZYK: I might have a vested interest, but from my perspective, with a large residential centre population there is a real opportunity to start testing and piloting some of the ageing-in-place accommodation support arrangements. If I had any issue, it would be that it gets through on Stronger Together 2 funding and we get some things happening. I did some statistics, and I am very happy to leave some of them with you, showing that we have a massive increase in the general population of over 65s. Within a large residential centre [LRC] population currently of about 300 people, 60 per cent of those are between 50 and 83. By the time we get building happening—and Paul understands the aged care building process very well—in five years time we will have another population backing up. I am suggesting there might well be another crisis, but it is a demand crisis, and we will not be ready to deal with it.

Mr SADLER: One of the challenges that I put on the table, which flows directly from Mike's point, is that the nature of the aged care funding system from the Federal Government's point of view is that it increasingly relies on the capacity for older people to have something to contribute in order for aged care building to proceed. You would probably be familiar with the debate about accommodation bonds in aged care. There is currently a Productivity Commission inquiry to which we have also forwarded a submission on behalf of the Futures Alliance. One of the big debates there is how we will be able to build the aged care accommodation in the future that Australia needs.

Clearly, for a group of people who have been in a large residential centre or indeed in group homes accommodation and who do not have their own home with which to provide access to construction of aged care buildings for them, the Federal Government has a component of its aged care funding system that is called concessionals. They receive government funding towards accommodation payments. The argument we have is that the level at which aged care providers are funded by the Federal Government is actually insufficient for the construction of new nursing homes in particular. This will be a particular challenge for this group of people. They are not going to be people who, by and large, will have their own accommodation because they have been long-term people with a disability.

The Hon. GREG DONNELLY: Assets?

Mr SADLER: They are not going to have a lot of assets. They may have worked, but probably not in a high-paid job. They are not going to have a lot of money to bring to the table in terms of their long-term accommodation needs. It means that between the State and Federal governments, it is highly likely that some form of capital funding assistance will be required.

It has been interesting that one of the projects that has proceeded to some extent in ADHC's own network is the plan to close the Peat Island centre and move what is a very ageing group of people from that centre to new accommodation on the Central Coast. They have had to capital fund that project. They spoke with the Federal Government about the possibility of accessing aged care funding and there really was no way that that was going to work. That has been a project has been funded by the State Government for, effectively, a group of older people.

The Hon. GREG DONNELLY: In relation to the issue of the need for more and better consultation with older people in terms of their needs, how do you recommend that ADHC and other government departments coordinate consultation as a process to ensure a better understanding in homes and better outcomes for this particular group of people? If you have not thought about it, you can take the question on notice, but I am hoping you will be able to respond.

Mr BLASZCZYK: I suggest that they might think about using some of the peak bodies that represent the interests. My own organisation has just done a major consultation process that was facilitated by the New South Wales Council for Intellectual Disability. We know that the feedback and results they achieved through that facilitation will be an accurate portrayal of people's views. It was specifically related to ageing and the way they saw their futures. It was for the Federal Senate's inquiry that they were doing it. They made a DVD. I will be very happy to share a copy of that DVD, after I ask their permission.

The bottom line of the consultation is that they are living in an institution and they do not wish to age and be reinstitutionalised into a residential aged care facility. They actually want the opportunity to have a decent life out within the communities where their friends are.

Ms HEWITT: I would add that, by using the peak organisations, you not only get that level of qualitative information but also, as I observed from people to whom you spoke earlier, people who are not in touch with ADHC services and who really need to be consulted about these issues. I am referring to people with disabilities who currently are not accessing those services that are either provided or funded by ADHC. It is often those peak groups that are in touch with those people.

Mr BLASZCZYK: And they trust them.

Ms HEWITT: Yes.

The Hon. GREG DONNELLY: Because of the relationship they have?

Ms HEWITT: Yes.

The Hon. GREG DONNELLY: I will move on to a matter that has received some ventilation during the inquiry, and that is the issue of self-directed individual packaged funding arrangements. I will leave it to you to open up and express your views and thoughts about that. Different perspectives have been put. If you have read *Hansard*, you may have seen that we have a general sense of moving away from the old approach, which was institutionalised and very sort of rigid, through to advocates who have gone so far as to say that individualisation and should almost allow people to take risks and even make mistakes.

I have been struggling with respecting the autonomy and personhood of people who have a disability, but knowing in many cases they need a helping hand and perhaps even some quite firm guidance to make a decision and, without being presumptuous and telling them what to do, how you achieve that balance. The issue of the individual funding option really seems to be a big issue that is central to that very matter, and I am wondering what your thoughts are about that.

Ms HEWITT: I think that the move towards individualised funding and even self-managed funding is a very important step. Certainly I think it addresses the need for people with a disability to be in control of their own lives. As you say, though, that can look different for different people. There are some people and some families who can make those decisions, and who wish to, and others who may require immense support and may in fact also require, or want, an organisation to take some control of that.

As a principle, that is something that we absolutely should be working towards, but we should also put in mechanisms that enable people to have that support. I agree that there needs to be a certain level of risk-taking. One of the difficulties with the system currently is that people often are getting service, and sometimes they are getting too much service because they have to fit into what is on offer. They ask for something and they do not get it. They might require low levels of support, but that is not given at the right time. When the crisis hits, they actually have to have a 24-hour option, or they might want to do lots of different things during the day but get stuck into a day program because that is all that is offered. Then they might be overserviced in that environment.

Individualised funding can recognise that. We can use the informal supports that people have in the community and we can tap into whether their friends and families can do something with a smaller amount of money than it would cost for a paid carer to do something. I am not proposing that we exploit people, but people who have their own resources often will come up with very creative options that are much more cost effective. At the same time there do need to be those mechanisms whereby there can be either a broker or a supporter. Organisations can be there to enable people to plan both from the outset or when things change. So people might be in a position in the first place to start off and support their son or daughter to manage their self manage package, and then something happens, marriage breakdown, or the carer is older or becomes ill, or circumstances change in the family and that can no longer happen. There needs to be a mechanism to step in and support that.

The Hon. GREG DONNELLY: It has been argued by some witnesses in their view about the shortage or lack of support for people with mild disabilities. Some people have said very strongly that it is a real shortage. In the context of older people with disability and older people with mild disability, could you share your thoughts about the level of service that the State offers to them?

Ms HEWITT: Yes. I think it is a huge issue that often we judge people's level of disability on the basis, and I know we have functional assessments, but in terms of ADHC services it is often on the basis of an IQ score. We know from our practice that people do not function in the community or in their families, or in life in general, according to what their IQ is. It is a very complex arrangement of what internal resilience and resources they have, their personality factors, their family members, the experiences that they have had in life and whether or not they have an underlying psycho-social disability for example. Someone with a mild disability can actually have higher support needs than someone with a severe disability who might have family members around them or who might have other personal resources that they can draw on. So having an arbitrary cut-off point for someone to access service, we know really does not work. That can be said for people at the very early intervention level, as well as people who are ageing. Typically the people we are dealing with who are ageing with a disability, who might have not met requirements or eligibility for service, once again there are those overlays—whether or not they are ageing earlier, whether they are experiencing those ageing needs earlier, and they might not even have a disability service in place.

Mr SADLER: I just add that we do know from the Australian Bureau of Statistics (ABS) study on ageing disability and carers—it is a bit dated now because it is 2003—32 per cent of people aged over 65 reported unmet needs for help of one form or another. What was quite interesting when they did a split on disability type was in actual fact there were as many, if not more, people with relatively lower levels of disability and handicap who reported having unmet needs than the people with more severe disability. So there is some statistical evidence in the ABS survey that backs up what people have said to you. I should comment that that is all older people, and we are of course focussing particularly on that subgroup of people who have long-term disabilities who are growing older from the Futures Alliance point of view, but I suspect, as Joanne has said, the same would apply.

The Hon. MARIE FICARRA: Dementia—we know it seems like a tsunami heading our way. Does Alliance have any plans that you are looking at in the future? Do you have any recommendations to government departments as to how they should handle planning for the future?

Mr SADLER: The first comment, we would certainly agree with you. It is a very significant condition. All the statistics show that the increase in people with dementia is going to be substantial in the next 40 years. It is directly linked to the ageing of the population. The proportions of people with dementia, once you get above age 80, you have got a better than 25 per cent chance of having some form of dementia. What we also know, particularly for the group of people we are here today representing today in the Futures Alliance, is that there are certain types of disability, one being Down Syndrome, where there is a much higher likelihood of early onset dementia. It is quite common for people with Down Syndrome to develop dementia in their 40s and 50s, which puts them obviously in double jeopardy, if you like, in terms of their needs.

One of the reasons that underpinned the formation of the Futures Alliance was that we could see there was potential in this group of people who were going to be affected by dementia, who in a sense, as Jo-Anne said earlier, are an emerging group, they have not lived that long because of their underlying longstanding disability. We have got better at health care support for those people, but they are now developing secondary conditions, particularly dementia, which really they were not getting before because they did not live long enough to contract the disease. We are very concerned about the particular needs of those groups and it is an area where it is really important that the ageing and disability sectors work together. Here today were representatives of the aged care sector. We have the expertise in dealing with the needs of people with dementia. My colleagues here have the expertise of dealing with the needs of people with a disability. We both need to be working together to help those people who are going to be having both sets of problems at once. What we certainly hope will happen is that this particular subgroup of the tsunami of dementia will get attention as part of the overall responses that Federal and State Governments will need to be putting into place for dementia services.

Ms HEWITT: I mentioned before about the gap in terms of assessment processes. That is one of the things we have identified, both in terms of assessment, but as well in terms of the training and upskilling of people who are working with people with a disability, so the direct care staff in particular, in actually identifying dementia. It is a much more complex group. Dementia is often difficult to identify in the general population. It is often only after something significant happens that people trace back and say, “Well, dad was forgetting his keys all the time”, or whatever, but with someone with a lifelong disability, and particularly an intellectual disability, that is much harder to unpack, or someone who has very limited communication skills. We would like to see both better assessments of people's disabilities in the first place and better identification as people go through as to when those ageing processes are starting, so it can be addressed in the early stages rather than waiting until the penny drops, and also training of staff to be able to identify what are aged care issues and how that is separated from a person's lifelong disability issues.

The Hon. MARIE FICARRA: It has often been said that for people who work within the disability sector and the ageing sector, we need to make it more attractive, with better training, better pay. What are your views on being able to handle the challenges ahead of us in terms of what people expect the number of people that are going to be requiring care—training, pay issues?

Ms HEWITT: All of the above I think. We as service providers find it increasingly difficult to recruit staff into positions. I think there is both the issue of the types of salaries and conditions that people are provided as well as the very nature of the kind of work that we are asking people to do, particularly when you get a cohort of younger people who are coming out expecting that they are going to work in nice clean jobs, that they are going to travel a lot and things like that, and that is not the lot of somebody who is a paid carer. Those are the kinds of things that we as service providers we are constantly facing, how to both reward our staff in the way that we need to, but attract good staff to those kind of positions, and attract staff who are fit and healthy enough themselves. It is often women who have raised their children who feel the desire to become a carer, which is wonderful, but they are often the people who are not physically in a position to do some of the work that we are requiring them to do.

Mr SADLER: I would also add that I think it has been quite encouraging to see that ADHC has identified workforce issues much more in the last couple of years. I note that Jim Moore, in his presentation on to the Committee on the first day, talked about some of the work that they have put in.

Ms HEWITT: And some specific projects with NDS.

Mr SADLER: That is right, and I think we would echo that that has been very useful. They have also been doing some work on the training framework for the home and community care workforce. So they have recognised that this is a critical issue. From a service provider perspective, we have all been in ageing and disability sectors putting a lot more effort into the training of our staff. The remuneration issue is of course a more difficult one for us to actually address because to a large extent our capacity as employers is linked to the income we receive, which is predominantly government funding. There is a proportion of funding that we get from fees and so on, but again most of the recipients, both in aged care and in disability, are pensioners so there is not a lot of extra funding you get from that source in reality. I think we would echo the feedback you have heard from others that it would be really useful to be able to move on those areas but it is a pretty difficult job. We understand the constraints on government budgets as well. It is not easy for us as a society as a whole to move substantially on pay rates for what has traditionally been seen as women's work and somewhat less important perhaps than other better remunerated sectors that are useful like lawyers and so forth.

The Hon. MARIE FICARRA: Your individual organisations coming together under the umbrella of the alliance, do you believe that it has produced benefits for your individual organisations in terms of being able to plan better to give better services?

Ms HEWITT: Absolutely.

The Hon. MARIE FICARRA: If this is the case would you advise other non-government organisations to be looking at something like this?

Ms HEWITT: Absolutely. I think there have been a number of advantages to the alliance coming together. I think the brains trust has been incredible to be able to share information about both the different funding mechanisms as well as—from the disability point of view we have learnt so much from the aged care providers in the room about how they operate and the constraints that they operate in.

Mr SADLER: And vice versa.

Ms HEWITT: Yes, and vice versa. Of course we have academics and peaks around the table so we are getting the latest research and have been involved in some research projects. But there have been some really practical examples I think of service providers coming to the table and talking about an issue they might have with a particular person and somebody puts their hand up and says, "I know someone who can help with that". So there have been some nice connections made there. We have kept deliberately small as a group, and it is not a funded organisation; it is just a group of us sitting around a table. At the moment I think we are up to about 22 members and we have kept that deliberately small so that we can be purposeful and so that we maintain the energy around the room. It is not just about how many people we can get around the table but it is about what kind of work we can do but we are looking at mechanisms to be able to invite other people to join in that discussion. So at the moment we are opening that up to other organisations to share in our information and be part of that, but yes, absolutely, I would commend that kind of process to people.

The Hon. MARIE FICARRA: And your ability to—I hate using this word—lobby or represent the needs of your client base, are you being heard by ADHC because you have a stronger voice and a united, coordinated voice?

Ms HEWITT: Yes, I think there is some notice being taken. Our experience has been that individuals have come and spoken to us but at this point we are not entirely sure what they want to do with that or where they see it going. I think they certainly see that our group has a number of people around the table who have something to say.

Mr BLASZCZYK: It would be really good to participate in the planning, the futures planning.

Ms HEWITT: Yes. I am not sure that ADHC knows what that looks like quite yet and how much we might be invited to do that but we are very hopeful.

Mr BLASZCZYK: We did collar Bill Shorten, or you collared Bill Shorten.

Ms HEWITT: Yes, that is right. Actually, where the blueprint came from was that we did see Bill Shorten some time ago and he said, "What we want is something I can put on one page that will tell me what it is about". So that is why we set about and said, "Okay, we will produce our"—we have a little poster that we produced. We were thinking about sending him a t-shirt but of course I am not sure that he will be in the same position for very long. We are certainly lobbying both State and Federal people at government as well as departmental level with the information that we are pulling together.

The Hon. MARIE FICARRA: If you had a magic wand and you could break up those large residential accommodation areas that exist around the State and utilise that money effectively to provide some better accommodation for your client base, how would you go about it?

Mr BLASZCZYK: I know what the starting point is—to go and talk to the people.

Ms HEWITT: I was just going to say something like that.

Mr BLASZCZYK: That is the starting point.

Ms HEWITT: Absolutely. We could say what we want it to look like and it might not be what everybody wants it to look like. It really is a question of—it is going to be different for different people, in the same way as we go around this room and we will all have a different view of where we want to live and how we want to live.

The Hon. MARIE FICARRA: Has anyone every done it? Has anyone actually gone and spoken to people in these large residential and said, "Are you happy? What would you like?"

Mr BLASZCZYK: Yes.

Ms HEWITT: The process is underway.

Mr BLASZCZYK: The people who live there, quite frankly, want a decent life outside of the institution. They want an ordinary life. Their ambitions are very modest. They want to live with people they like living with. They want an ordinary life, basically. Their families may have a different perspective and that is where you have to do the work.

Ms HEWITT: That is often based on fear and past experience.

Mr BLASZCZYK: You have to do the work with those families.

Ms HEWITT: Can I just tell you too that one thing we have not talked about, and it is not necessarily specifically about this, although a number of people who we deal with are ageing, my organisation does a fair bit of work in boarding house reform, assisting where boarding houses are closing and assisting to find support for those people who often have lived in fairly desperate circumstances for many years and they are often those people with the milder disabilities who fell through the cracks early on and did not get much so as their life circumstances change they have ended up in congregate care—care is not the word for it but congregate living situations where they have had to trade favours for cigarettes and live in fairly sometimes filthy and disease-ridden places. We have been working with some of those people to look at what they want, how they want to live.

Most of them, when you first ask them, have no idea. In fact they will often say, "I want to go to such and such a boarding house" because that is all they have ever known. But we have had some great success in actually supporting those people to live independently in the community with some drop in support, and that is sometimes on their own or it is with other people but they have lives that they never would have dreamt of. So asking people in the first instance, that takes a bit of work because it takes a bit of work both for the people and their families to understand what the options are. Often when you ask them at first, all they have ever known is the institution or the boarding house, and it does take some work to actually project to them that this might be possible.

The Hon. MARIE FICARRA: Even with the Government improving its regulation of such boarding houses, that even if this were to lead to those owners of boarding houses placing them on the open market because, for whatever reason, they no longer become profitable and therefore those boarding houses are out of the system, do you believe that it may be expensive for the Government at the time but in the long term it is a far better thing for your clients?

Ms HEWITT: To be out of the boarding house?

The Hon. MARIE FICARRA: Out of the boarding house.

Ms HEWITT: Absolutely. If I think of the genesis for some of those boarding houses, many of them were established by people with good intent, people who saw people on the streets or coming out of institutions or not having had any service who really required a place to live, and they have started off with good intent but having people living in those circumstances in a congregate environment will never work. It is never going to work. So absolutely people are better off out of it.

CHAIR: Would you like to make some brief closing remarks? Earlier you spoke about a good case study. Will you provide the Committee with a best practise case study in relation to a person who came out of an institution?

Mr BLASZCZYK: We can certainly take that on notice.

Ms HEWITT: Yes, absolutely.

CHAIR: The Committee may even want to meet such a person, and I am not suggesting we do that here.

Ms HEWITT: That would certainly be possible. We will provide that for you.

CHAIR: Do you have any final thoughts in relation to recommendations?

Mr SADLER: The final comment, actually Mike talked about the statistics, that we could leave with you if you wish, is that those statistics indicate that while it is still a relatively small proportion of people in the ADHC services sector who are over 65 at the moment—it is only around 5 per cent—the projections forward are that that proportion is going to increase markedly. So within a period of may be 30 or 40 years you could be looking at somewhere between 40 and 60 per cent of ADHC's clients in disability services actually being over 65. It is starting small but it could be another tsunami just in terms of numbers as we go forward. It does underpin why we here today. We can see this emerging group which is still relatively small in numbers now but it is going to be a much more significant component of the disability services system going forward, and also have its own impact on aged care as well.

(The witnesses withdrew)

MARGARET BOWEN, Chief Executive Officer, the Disability Trust, and

PENELOPE DESMAZURES, Executive Manager, Respite Community Services and Residential Services at the Disability Trust, affirmed and examined:

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

Ms DESMAZURES: As Executive Manager, Respite Community Services and Residential Services at the Disability Trust.

Ms BOWEN: As Chief Executive Officer of the Disability Trust.

CHAIR: Do you want to make an opening statement?

Ms BOWEN: I will start by giving a very brief outline of who we are and then perhaps outline what we see as being some of the critical issues affecting the delivery of quality disability services within New South Wales. The Disability Trust has been around since 1974. We were formed by people with physical disabilities and by parents of people with intellectual disability. We had, from the outset, very much an advocacy and rights-based perspective that has continued to inform our values position until today. We have as an underpinning mission to create an inclusive world and so while we have developed the sophisticated business models and practises that are required for delivery of services, still what motivates us is our values system. I think that the disability sector in New South Wales does some extraordinary things because we come from that standpoint of having a values perspective.

The Disability Trust receives 60 per cent of its funding from the NSW Government. We received in income $20.6 million on last year's figures. We do have Commonwealth funding and we also have funding from social enterprises and charity fundraising, the latter to value add to the service system and supplement what government does not fund. We operate a very broad range of disability services across quite a large area of the State—pretty much all the southern region of the State. We are very committed to building knowledge systems within our organisation so we have particular committees focussing on access and equity for disadvantaged groups and partnerships with Indigenous communities. We have a very strong focus on human resources, workforce development and training and a very comprehensive quality improvement system. I think that just gives a taste of who we are.

As someone who has been around the sector for a very long time—I have been with the Disability Trust for 23 years—I have to say that I think we are in a much more optimistic frame of mind as a sector than we have been pretty much for that entire duration. There were some very lean years in disability services funding, and I think that created a lot of angst between the community sector and government, and certainly between people with disabilities and government and funding bodies. I think the roll-out of Stronger Together has had a big impact, that is not to say there is not a huge job yet to be done, but we are seeing a sense of optimism from the people that we work with. I think that has allowed us to do something that is a bit exciting too, which is to move from that advocacy sort of push me, pull me situation with government into a feeling of much more being in partnership with our funding bodies. I think that there is this opportunity now to really look at how we design our service system for the future.

Some important issues that the Disability Trust has nominated to focus on its submission—and they are not comprehensive because we know the Committee has had a long day of hearing from other people that would say things somewhat similar to what we would say as well—are alignment between government policy and, in particular, one of the big new issues for us is the lack of alignment between disability policy, which is moving towards person-centredness, flexibility and choice, and Commonwealth industrial relations frameworks which are requiring increasingly inflexible work practises. This has led to significant costs. If you are doing flexible service delivery, and you are doing it right, and you are allowing your rosters to be changed on a daily basis to meet client need then you will come up against those sorts of barriers and it will cost you to deliver in that environment. It is also creating a casualised workforce as well because that is a response to a need to create, I guess, a larger workforce to cover some of the issues.

Another area that we see as being very important is duplication in Government accountability requirements and the compliance load on the disability sector. I think we are a very heavily regulated sector and I, for one, am very proud of the achievements of our organisation in terms of responding appropriately as we should to those accountability frameworks. However, we see ourselves asked the same questions about our governance structure, about our finance structure, about the overlapping disability standards, both Commonwealth and State. We are at the moment up to six forms of compliance, and this is outside of the normal corporate compliance with taxation law and charitable fundraising and all of that, just to do with the work that we do.

Dr JOHN KAYE: What do you mean by six forms of compliance?

Ms BOWEN: We have to comply with New South Wales Disability Service Standards, Commonwealth Disability Services Standards, home and community care standards, attendant care industry standards—it is a very long list. We also provide children's services for children with disabilities, so we have to respond to children's services standards as well. There is a lot of duplication. We are providing volumes of data to various branches of Government that I think could be a little bit more streamlined.

The other issue that I see is that we need, as a sector, to be developing more sophisticated integrated management systems for dealing with the way we are disaggregating care in order to have individualised funding. I will just give you an example. This is just in relation to respite and in-home care, not centre-based respite or group homes. Last year the Trust delivered 83,188 hours of respite and in-home care, but that was delivered in 27,628 episodes of care using about 200 staff over different durations of shifts, over different shift penalties. What that means is that the rostering, financial management, human resources and workforce development is incredibly complicated. That is a new thing. In the old days, funded services just opened their doors and said, "This is what you will receive". The management of those sorts of systems is not complex. Delivering flexible service systems is incredibly complex. Other issues include sustaining infrastructure around individual funding. It is all very well to say individualised funding, but people have to have the option of having the infrastructure there to access and sometimes that does not work very easily within an individual funding model.

The last thing I would like to say is—and I think the funding bodies and Government are doing this—recognising the impact of the not-for-profit sector on building social capital, on being able to leverage not just funding from the community in terms of charitable fundraising, but leverage goodwill, community connections and networks that we can utilise to support our clients in ways that I think ultimately does save on the funded dollar to Government. Finally, and this is my last paragraph—I am sorry, I have probably gone over a bit, but I realise you have not had a chance to read it—in terms of what the families want, we could come up with a shopping list of service models, but one of the things that we have done recently is survey our client group, which was in relation to the Productivity Commission inquiry at a Commonwealth level, but I think some of the things transcend that. We had 297 responses.

I am aware that it is only small in the scheme of things, but far and above any other thing that people wanted from the service system was assurance of service. They wanted a guarantee that their services were not going to be taken away from them. Even people who thought they were getting enough services at the moment—not that that was everyone—felt vulnerable. They felt vulnerable in relation to changes in political direction and they felt vulnerable in relation to, "Maybe somebody down the road is going to come in and want a service for the first time and they are going to have a higher respite need than I do and I will be bumped to the bottom of the priority list". While they did feel like they were starting to piece together some service delivery, they still felt very vulnerable in that environment.

Other things were about flexibility, which you know about, and quality of care. I think that there are people who are finding it very difficult to navigate their way around the service system, and that was another demand. There was some concern about regional, rural and remote communities in terms of levels of funding and support for infrastructure, and some interest in portability of funding individual packages. Finally, a significant number of people, although not as large as I would have thought, wanted self-managed care. The people who want that I think are very passionate about it, but I do not think that is a universal thing that is being requested. That concludes my overview.

The Hon. MARIE FICARRA: It is very difficult to keep attracting the right sort of caring people into the sector—pay levels are quite low, training perhaps needs to be improved—but in relation to industrial relations flexibility, as a Federal issue, what would you recommend, given that we are trying to individualise packages and make them flexible, according to clients' needs?

Ms BOWEN: I think that there is a lot of support in the sector for the pay equity case, but in terms of flexibility we have seen changes since the move to the Federal system. There now has to be a 10-hour break between one shift and the next in order for it not to almost automatically hit overtime rates. If you are talking about a person with a disability wanting respite, they do not want it while they are at school, they do not need attendant care or personal care when they are out during the day in the workforce, they need support around breakfast, getting up, assistance to get out the door, and they need it at the end of the day. If we cannot push those two services out to be 10 hours apart, if somebody moves their shift early by 15 minutes the entire second shift is at overtime rates. What that has meant for an organisation like ours is that we went from having virtually no overtime prior to December when the new award came in to expending $35,000 on overtime in the first six months of this year. The way we will address that is to increase the number of employees so that we are not tripping over that barrier, but that means we are casualising the workforce and picking up additional costs in training and workers compensation. It is very much a double edged sword and, as more and more agencies move to that highly flexible model, I think we will see them tripping over that barrier.

The Hon. MARIE FICARRA: High casualisation of the workforce would not be ideal for your clients.

Ms BOWEN: Absolutely not.

The Hon. MARIE FICARRA: They do not like seeing a new face too often. They like to build up relationships.

Ms BOWEN: Absolutely. It is not good for our clients and ironically the staff who have been with us for a very long time are not happy with it. The alternative is not that they are all going to be paid overtime because it is simply not affordable. The alternative is that we stretch out our workforce, and that is very sad.

The Hon. MARIE FICARRA: So, if possible, governments need to look at this. When I talk to people with disability or their family and friends they are crying out for more respite. How can you possibly satisfy respite needs? Does anyone keep a waiting list? Do you have any idea of the unmet need? It must be enormous.

Ms DESMAZURES: There is not a clear-cut waiting list for that. It has improved. I know that we have a lot less people whom we are unable to give any service to, but the under-met need is probably even bigger because a lot of people are getting a little bit of something these days but it is not always enough to meet what they need. They may be getting two hours a week when they could do with three or four hours a week.

Ms BOWEN: Or ten.

The Hon. MARIE FICARRA: What is the answer? Is it more places for respite care or more funding of what is available? How should we address this?

Ms BOWEN: We have to recognise that people want choice. However, having said that, I think that centre-based respite can be more cost effective in the long run. One of the things our organisation does is to have unfunded respite houses so people who have flexible respite packages can have the service in their home or they can say they will work in with a range of other families that have kids with similar needs. They use the Disability Trust's respite house for a period of, say, five days. You can translate small amounts because you are sharing staffing costs, and they are the big cost. The problem in doing that is that although it is very flexible it is like putting a jigsaw puzzle together for us to continually fill those houses because not everybody can share a respite facility with everybody else. There is behaviour and social needs and age compatibilities and all sorts of things.

One of the things we are doing as a social entrepreneurial model is that we have bought some facilities that are unfunded. One of those is on the waterfront at Sanctuary Point. It was a bit of a test really. It is a really lovely house and we use it for holiday rental to the general public over certain periods of the year and cross-subsidise our respite that way. Most holiday houses sit empty for a lot of the year but our house goes full-on throughout the year providing respite and then pulls some money back in for subsidies across the Easter and Christmas periods.

The Hon. MARIE FICARRA: Is it working?

Ms BOWEN: I think we took about $15,000 or $16,000 extra that we would not otherwise have had. There is an argument that families should have access to it at Christmas as well, but again we are trying to stretch the dollar and make it go further and be a bit creative in what we do.

The Hon. MARIE FICARRA: Have any other organisations tried this entrepreneurial approach?

Ms BOWEN: Not that I am aware of in terms of double use of a property. Certainly there are a lot who have unfunded respite houses that do the same sort of work we do in trying to stretch the dollar by co-locating people.

The Hon. MARIE FICARRA: In terms of conflicts of interest that ADHC might have, if you look at complaint handling, quality monitoring, program evaluation and similar issues, do you believe the sector needs an independent arbiter where there are conflicts of interest and complaints from clients about various service providers, or do you think ADHC handles it well?

Ms BOWEN: That is very difficult. Independence is ideal but there needs to be more collaboration between people that require compliance from not-for-profit organisations, government-funded organisations. We had a two-week audit by ADHC and we have an audit every year by the Commonwealth. The bulk of it is the same. They say, "Talk to me about whether you have a strategic plan and an annual report. Show us how you handle your finances. Show us your quality improvement system. How do you manage and track these sorts of things?" We feel like we are saying it over and over again. I think it could be streamlined. It would reduce red tape enormously.

The Hon. MARIE FICARRA: So, streamlining of monitoring, funding and performance and there should be coordination between the various State and Federal departments. Perhaps there needs to be one body that you can give that information to. Would that work?

Ms BOWEN: I think it would. The Commonwealth already uses independent auditors that are accredited through the Joint Accreditation System of Australia and New Zealand [JASANZ]. It is the accreditation body for organisations that deal with standards.

The Hon. MARIE FICARRA: That seems to be a very sensible way of not wasting your time in giving the same information to a multitude of government departments at both State and Federal levels. What about information for clients? There are a lot of complaints that there are myriad services out there and people do not know where to start or how to coordinate well if they are looking after a family member with disabilities. Is there a place for having one body or organisation to coordinate this, or is that too simplistic?

Ms BOWEN: I think that is very hard to achieve. People do not need to know everything until they need a service and the service system both inside and outside disability has a lot of opportunities and a lot of things to deliver. I do not know whether you could get away with having one body. People do need some assistance and case management is great, but one of the problems is it then pulls back money from service delivery. It is almost like having a choice between a slightly messy fragmented service system that is hard to navigate and building something else that might mean people get less service delivery on the ground. I do not know the answer to that.

The Hon. MARIE FICARRA: Has there ever been consultation with service providers as to what would be the best system? Have you ever been asked to participate?

Ms BOWEN: Over probably the last 20 years there have been various calls for one-stop shops but every time you try to build them it is hard to get the scope that means it is a one-stop shop. The one-stop shop becomes bigger than the biggest supermarket and it makes it unrealistic to deliver. I am talking without having thought the answer through. Maybe some containment around that would be one way of delivering it.

CHAIR: The shop becomes a shopping centre owned by a multinational!

Ms BOWEN: Absolutely.

Dr JOHN KAYE: We have taken evidence on the issue of relinquishing of children with disabilities. It is all heart wrenching. Parents say that the only way they can get their children into supported accommodation is by relinquishing them to the care of the State. This is a really serious issue.

Ms BOWEN: Yes, absolutely.

Dr JOHN KAYE: It really needs to be dealt with. I will begin by asking you how prevalent you think the problem is.

Ms BOWEN: I think it is prevalent. It has been prevalent. I think it is changing a little.

Dr JOHN KAYE: Is it getting better?

Ms BOWEN: It is getting better. I think one of the flipsides is complaints from families who just keep on keeping on—"Maybe my level of care was just as high. Maybe my need was just as significant, but I am not prepared to do that, morally and ethically, therefore I get nothing." I think that is a hard argument to hear. It is equally hard to hear the sad stories of people who have relinquished care in those sorts of dramatic circumstances.

Dr JOHN KAYE: What is the way forward? How can we get supported accommodation for those people without them having to relinquish their children into government care?

Ms BOWEN: I have to say that there are various levels of awareness among families of a waiting list. I have just met with some down in Merimbula who thought they were on a waiting list but, as it turned out, somewhere along the line across the last 10 years something happened, and they are not on the waiting list anymore. When people think there is a waiting list, it may be a long wait, but it is better than thinking that there is no door that is ever going to open.

Dr JOHN KAYE: Is it true that waiting lists like that work better when they are transparent and people are aware that it is progressing?

Ms BOWEN: I think transparency would be a good thing. I realise that it is very difficult for the department. We have come from a period of crisis management and relinquishing care and we are now moving into a period of funding. As a service system, we need to start finding ways of collecting information in a more rigorous way. We did not collect a waiting lists 10, 15 or 20 years ago because we were waiting for nothing. The train was never coming.

Dr JOHN KAYE: I take it from what you are saying that there is now some hope that the train will arrive.

Ms BOWEN: That is right.

Dr JOHN KAYE: But some people are losing confidence in that.

Ms BOWEN: That is right. That is exactly it.

Dr JOHN KAYE: One of the things that needs to happen here is that there needs to be more confidence given to those people.

Ms BOWEN: I think so.

Ms DESMAZURES: There are also issues in terms of waiting lists when people see their name is not progressing because there is always someone with higher need. The person in crisis jumps to the head of the queue and that can be very disheartening for families as well. That is one issue in terms of a fully transparent waiting list. A family sees that they are advancing very slowly and feels that they will never get there whereas others are jumping to the head of the queue, and that can create issues. It is a bit of a catch-22 with those things.

CHAIR: Is there not also a whole host of other variables involved in defining a waiting list? You might be waiting for—I will not say train, bicycle or plane—a State, Federal, NGO or government program. It would be difficult to have a waiting list that encompasses all the variables. That is what you are saying about the dozen or so attempts over the last 30 years to implement a waiting list.

Ms BOWEN: Yes. I do not have the answer, I am sorry. It seems that there is always a compromise between the sort of messiness of the system and the idea that we could have a perfectly rigorous and neat solution for people.

CHAIR: And the more flexible and more customer orientated we make the system, the more elusive the waiting list becomes in many ways.

Ms BOWEN: Yes.

Dr JOHN KAYE: One of the things we have heard a lot about, which is heartening news, is that people with disabilities are living longer, and that is to be welcomed by everybody. But that means not only are they getting older but also the carers are getting older. Do you have evidence of that? Do you think this problem will create even greater needs? How can we support older carers?

Ms BOWEN: I think it is a huge problem already. It has been a huge problem through a number of years. We have seen cases when the first accommodation that someone has had has been when their mum, who is in her eighties, finally goes into a nursing home or, even more sadly, dies. We have a long way to go to improve upon the system.

Dr JOHN KAYE: Can you give us some directions as to how we could ease some of the burden? Carers throughout their lives have a challenging time, but carers who are in their sixties, seventies or eighties are clearly facing an uphill battle. How can we take the stress off them?

Ms BOWEN: I think we need more supported accommodation options. At the end of the day there is a big resource issue behind it all. It is hard to think of ways. We can be very creative as a service system, but we cannot do something with nothing. If that train is not coming, there is a limit to what we can do. Perhaps we should be prioritising elderly families.

Dr JOHN KAYE: There is not a partial solution which involves providing more support to elderly carers? I am not taking away from the urgency to create more supported accommodation; that is clear. There may be some people who want to maintain the carer relationship but are finding it physically and emotionally demanding as they get older. Are there things we can do to support people in that relationship?

Ms BOWEN: I think that we can put in intensive in-home support, but often the service provider ends up becoming a de facto service provider, I think it would be true to say, for the elderly person as well, which makes it quite hard. There are issues of what we call co-dependency where the younger person with the intellectual disability is taking over quite a lot of the physical tasks and the family needs support as a family unit in those circumstances. It is very difficult.

As a service provider, we are not funded to provide the support service to the family. It is something that we again have to stretch capacity to do. I think it can be done but it means that the Commonwealth and State have to agree on how they work collaboratively to provide that, given that aged care is predominantly a Commonwealth responsibility.

Ms DESMAZURES: We do see quite a few instances when a family does not want to move immediately from nothing into accommodation. They are looking typically at personal care support and respite support to bridge that gap from when they realise that they cannot cope on their own, but they are not ready to have their son or daughter move to a group home. As Margaret said, we have a lot of situations where we are providing support to a 55-year-old person with a disability and to their 89-year-old mother who has dementia so that dad can go out and have two hours break in the middle of the week. There are quite different needs between the son and the mother, but you need to bridge those and try to work around that as well.

Dr JOHN KAYE: Is there a capacity bottleneck? Do we need to be putting more resources into support for that kind of situation?

Ms DESMAZURES: It is probably a lot better. Probably five years ago there was a definite need for it, but a lot of money has gone into the aged care area. There will always be those who need a lot more than they are getting and there will always be those who miss out, but from the reaction we get from families and the requests we get, my gut feeling is that that is probably not the greatest level of need at the moment in terms of those services. We usually find something with which to bridge as they need it in the short term.

The Hon. HELEN WESTWOOD: You referred, both in your submission and in your address to us, to the difference in services for people in regional and remote areas of New South Wales as opposed to what is available in the major cities. Could you elaborate on that? Are there some particular types of services that are less available, or is it a quality assurance and a skill issue outside of Sydney?

Ms BOWEN: It is a quality and skill issue and it is a cost issue. We work with some people who live in very small towns. Finding and training staff in those environments is very difficult. If we cannot find staff that are available in a town of three or four hundred people or we have utilised, exhausted that community, we have really got to pay travel for people to come an hour down the road or half an hour down the road, because people just will not drive for an hour to work and drive home for an hour. There is no way of doing that other than to provide an incentive, and that is not something that funding covers traditionally.

There are issues about service infrastructure. How do you build service infrastructure when people are spread? You can see in Sydney you will have half a dozen people living fairly close to each other, you can put a group home or whatever service type down. There needs to be a lot more planning in regional and rural areas to know where the best sites and locations are so that people do not have to move out of the area all together to go to Sydney or Wollongong or somewhere with a bigger infrastructure. They still need to have something close. There might not be one in every town but we need to look at the data and the demographics and the demand side a lot more closely to build that sort of infrastructure.

Ms DESMAZURES: Some of the response to that is using more flexible services. We have one example at the moment of a family which lives a distance out of Young and there is nothing in their local town in the way of services. Mum wants her daughter to go swimming in her respite time. We drive 300 kilometres round trip to take that person swimming. You say that is ridiculous, but there is nothing else. There is no bowling, there are no movies. There is probably a park around the corner, but if you actually want them to do anything, there is nothing in the immediate area. So we do that travel, not a problem, but the cost of transporting that person there and back has to come from somewhere, and it is not funded for. You get the same funding for that person as you do for someone who lives in town where it is a ten minute bus trip round the corner to get to the swimming pool or wherever else you want to go.

Ms BOWEN: We are a larger service provider, so we have some economies of scale, and we can almost cross-subsidise amongst our own organisation to provide that. If you look at the business case around that, whether you could do it if you were a small organisation and that was your only source of funding, I do not think you could do it.

The Hon. HELEN WESTWOOD: Is there a deficit of a particular type of service in regional and remote areas, for instance is accommodation better provided for or is it even less adequate?

Ms BOWEN: I think accommodation is less adequately provided for and I think that the issues we were talking about, people knowing how to get onto waiting lists and where to go, are amplified when they are away from big metropolitan centres or even big regional centres. People do not know there is such a thing that they can ask for, because it is nowhere that they can see.

The Hon. HELEN WESTWOOD: The issue you referred to earlier in terms of the Federal IR laws, is that more of a problem in those more remote areas?

Ms DESMAZURES: Absolutely.

The Hon. HELEN WESTWOOD: Or servicing those clients who live outside Sydney. Have you found a way around it?

Ms BOWEN: We have looked at every possible solution in terms of workforce development in some towns, including putting signs on the notice board for the mums at the local schools, in the one shop in town, and sometimes we can do that and sometimes we wear the cost of extraordinary travel to get people the service that they need. Now that the same person cannot work in the morning or the afternoon or often cannot work morning and afternoon shifts, it has meant that we have got to find more workers again in areas where it is really hard.

The Hon. HELEN WESTWOOD: Have you spoken to the Government or the union about this? Have you been able to convey the difficulty that the new laws have presented to you and looked at an opportunity to work through a resolution?

Ms BOWEN: We have spoken to quite a lot of people. We have spoken to the union; we have had a meeting with the union about it. I do not think that people realise just how hard it is, and I do not think that people realise it until they get to the point of genuinely trying to implement person-centred responsive service delivery. A lot of people think that that is just about having an individual plan. It is much more than that. It is about real day-to-day choice, and when you get to that very crunchy end of it, these are the problems that you will run into. I do not know, I do not want to be the flag flyer for the Industrial Relation Commission as just one organisation. We will have to do something, maybe an EBA. I do not know, but we will have to address it.

The Hon. HELEN WESTWOOD: Are other disability organisations talking about the same problems? Do you know if other organisations are sharing that experience?

Ms BOWEN: Some do. In the Home and Community Care area, which provides some of the respite care, there are different options because you have got an aged care clientele as well. That means that you can employ more permanent staff, because it does not really matter if the elderly person is getting up and having their breakfast at 10 or 10.30 a.m. You can sequence people. You cannot do that in disability because everybody has got to have their care at the same time in order to be somewhere during the day. It reflects the size of our organisation and specialisation of our organisation in the disability field to some extent.

Ms DESMAZURES: And we are already in the Federal arena, which a lot of organisations are not.

The Hon. GREG DONNELLY: Thank you for coming along this afternoon and speaking to us. Some of this has been covered before. Forgive me for revisiting it. It keeps coming up as a theme time and time again. The issue of us having a comprehensive understanding about the unknown need for people with disability in New South Wales, the thing that struck me is that a number of witnesses have said that they see it is an issue because there is no rigorous way of maintaining some form of record of that amount of unmet need. Could you give us your thoughts on that about firstly whether you share that view, and, secondly, if we were to develop some thinking around this issue of trying to get a picture of what the unmet need is in New South Wales for people with disability, how would you recommend that the Government would go about that? I am giving you a wide scope to reflect and comment on.

Ms BOWEN: Yes, we absolutely agree that there is a need for better data collection and monitoring of unmet and under met need. How you go about it, to be quite honest, I do not know. I do not have the level of understanding of statistics and ways of generating that sort of data. It is a very big picture.

The Hon. GREG DONNELLY: Perhaps if I approach it from this angle: You would agree that people with disability, not in every case, but often come in contact with non-government organisations of one sort or another that have an interest in their disability and advocate on their behalf. Would that be a fair statement?

Ms BOWEN: That would be true I would think, yes.

The Hon. GREG DONNELLY: That being the case, do you think such organisations, if this was done in a consistent way across the various NGOs, would be suited to collect certain information about unmet need?

Ms BOWEN: I think it is feasible. I do not know how you would construct that process, whether it could be built into the data returns we do to government. I do not know how you would construct that because it seems to me it would be quite a big effort, but I think it would be worth doing personally.

Ms DESMAZURES: The difficulty with doubling up, you would have to collect quite a bit of information so that you know that your list was different to my list and that we are not counting the same person six times. That is a big problem. The other thing that I think needs to be better recognised is planning ahead for some of the milestones in life. A lot of the clients we are talking about have had disabilities from birth, yet it seems to come as a great surprise when suddenly they are 17½ and they are coming out of school and changing services. It comes as a great surprise when they are 55 and looking to reduce their employment. All of those milestones in life that we can have predicted for the last in some cases 50 odd years seem to hit us as a shock all the time, and we come forward and say, "We've got 50 people retiring from work at the end of this year. What are we going to do with them?" Surely we could have predicted that 60 years ago. Some of those sorts of things need to be better done in terms of modelling and planning ahead for needs in the future.

The Hon. GREG DONNELLY: Let me put it another way. In terms of this—to use your language—modelling and planning ahead, who in your experience inside the sector does this pretty well in your view? If we are looking for a good benchmark in the way in which an organisation—it might be a government department or even within the government department, some section or part of a department—does this well? Does anyone?

Ms DESMAZURES: I think they are nearly getting there in terms of the school leavers moving into day programs or transition to work. That seems to be happening reasonably well and there does not seem to be the crisis happening there these days. It seems to be planned through a little bit. But other than that, I do not know that there is anyone doing it very well.

CHAIR: Can you say why that is?

Ms BOWEN: Because it is hard. I do not know. It is hard.

CHAIR: Sorry, I meant that area that you are talking about, it is done well at transition from school to work.

Ms DESMAZURES: It is possibly because it is such a clear deadline that that happens; they are going to finish school in December.

CHAIR: And they clearly know the numbers.

Ms BOWEN: Yes. Schools can count.

CHAIR: And schools can count.

Ms DESMAZURES: But it does not seem to happen with the same deadlines for children leaving care, like the transition at 18 from other services.

CHAIR: But the clear difference there appears to be, on face value, it is easy to measure the need.

Ms DESMAZURES: It is, and there is a definite place for them to move on to, because we have a lot of services that they graduate from at 18. If there is nowhere for them to go, then you do not do the same sorts of processes in terms of getting them prepared to transition because there is nowhere to transition to.

The Hon. GREG DONNELLY: Just related to this, and it has also come up in other evidence, this notion of people being out there with a disability who are disconnected completely from a representative organisation or advocate or even a government service—in other words, they are out there and perhaps are in the older cohort and are just almost completely uncounted, if I can use that word—do you have a view about that? Do you think that such people are actually out there? If you do, would they be in any significant number?

Ms DESMAZURES: We probably come up with one or two people a year who come to us through our emergency services where they present to the hospital or to their GP and mum cannot care as of now, and we take on services from there if they have no connection that we are aware of since they left school.

Ms BOWEN: We are probably like the front line of that whole emergency service. It can be quite a challenge because you have no history—

The Hon. GREG DONNELLY: No, that is right. That is what someone said.

Ms BOWEN: —and you end up with a person and you have to work out what they need very quickly. But I do not think there are volumes of people in that circumstance.

The Hon. GREG DONNELLY: You are saying people are reasonably well informed about the possibility of services and advocacy and support.

Ms BOWEN: I think so.

The Hon. MARIE FICARRA: In your submission you say that maintaining quality of care was ranked third highest by your client group after surety of services and service flexibility. You go on to say that perhaps this quality of care can be maintained at a good level by setting minimum standards applicable for both service providers and apply also to case management arrangements. My question is: Do you think that this should be something set by ADHC and then monitored by an independent—I hate to give you any more monitoring or administration or whatever; this is not reflecting on your service provision but you have so many providers? Do you think that there is a case where there should be independent monitoring of the quality of services that are provided?

Ms BOWEN: As I said before, I think independent monitoring is ideal. I think I have mentioned here that this was a survey in response to the Federal Productivity Commission disability insurance model inquiry. While people were saying quality of care was an issue for them, a lot of them were frightened in a transition to a new model of care that they would lose the sorts of valued relationships that they currently had with service providers. I know that because I read a lot of the commentary that underpinned it. So yes, it was ranked highly. And you would think it should be as well. But they were definitely not saying that they did not think they were getting quality services; it was about fear of—

The Hon. MARIE FICARRA: About the context.

Ms BOWEN: Yes. The fear of change.

Ms DESMAZURES: In our sector the quality cannot always be measured by a form that you fill out and someone comes in and sits down and says, "How do you do this?" and you say, "I ticked the boxes". I think quality measures need to be broader than that.

Ms BOWEN: Organisations like ourselves however would measure quality independently ourselves through quite extensive surveys of our client group, of our stakeholder group, the organisations that we work with that are also providing a level of external scrutiny and other people. We look at things like complaints, all of these things are what drive our quality improvement processes. I am sure it is not uniform but I think a lot of organisations would already be driving their own quality systems.

CHAIR: Is there an agreed regional structure within the industry in New South Wales? When I say regional structure, each government department has a regional structure. There are 13 regions within the Health Department. In the industry do you have an agreed regional structure?

Ms BOWEN: ADHC certainly has regional structures and we know how we fit into that, but again yes they would not align necessarily with other services that we provide that are funded from other sources because they have different regional structures, and there are issues around boundaries and being aware as we are as a service provider that works across more than one region of clients that could benefit from services that are not that far apart geographically but are not known to the other part of the department is an issue.

CHAIR: You may gain some economy of scale by having similar regions—

Ms BOWEN: That would be good.

CHAIR: —and being able to come together.

Ms DESMAZURES: If nothing else, it would make it easier for families to work out who they needed to talk to because this minute you are saying, "No, you need to ring Queanbeyan." Next minute you are saying, "No, you need to ring Sutherland" or you need to ring wherever else and they do not know who they need to talk to.

CHAIR: Do you have any final comments you would like to make?

Ms BOWEN: No. We are happy that we have been given the opportunity to talk to people.

CHAIR: We appreciate you giving us your time, experience and expertise. Did you want to table some documents?

Ms BOWEN: I did say I will table some documents: our annual report and some brochures and packages on some of the services that we offer.

(The witnesses withdrew)

(The Committee adjourned at 4.40 p.m.)