Corrected proof

REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON SOCIAL ISSUES

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

At Sydney on 26 August 2010

The Committee met at 9.30 a.m.

PRESENT

The Hon. I. W. West (Chair)

The Hon. G. J. Donnelly
The Hon. M. A. Ficarra
Dr J. Kaye
The Hon. T. J. Khan
The Hon. M. S. Veitch

CHAIR: Welcome to the second public hearing of the Standing Committee on Social Issues inquiry into services provided or funded by Ageing, Disability and Home Care. Today we will be hearing from the University of New South Wales School of Social Sciences and International Studies, the New South Wales Council for Intellectual Disability, The Benevolent Society, Spinal Cord Injuries Australia, the Multicultural Disability Advocacy Association and Northcott Disability Services.

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

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

EILEEN BALDRY, Associate Professor, School of Social Sciences and International Studies, University of New South Wales, New South Wales 2052, affirmed and examined:

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

Dr BALDRY: I am appearing as an Associate Professor from the School of Social Sciences and International Studies at the University of New South Wales.

CHAIR: I invite you to make some opening remarks to the Committee before we go to questions.

Dr BALDRY: I will open by giving a bit of background to my involvement with Ageing, Disability and Home Care [ADHC] and the Department of Ageing, Disability and Home Care [DADHC], and all its former incarnations. For about 12 or 13 years I have been involved in various forms of research with regard to people with disabilities and families with children with disabilities. Some of that work has directly involved ADHC, some has been funded by the Commonwealth Government and some has involved other forms of research funding.

My first major piece of research work with DADHC or ADHC involved looking at the outcomes for families with a child with a disability with three of the agencies that ADHC was funding at the time. The pilot projects looked at brief intervention—that is, intensive family support intervention—for families with a child with a disability. That included Northcott Disability Services and one other group. I will be happy to explain a little about the outcomes and what ADHC policies and programs resulted from that research. I have also been involved in a follow-up to that as part of the roll out of some intensive family support programs and in their evaluation.

I have also reasonably recently been involved in looking at people with mental health disorders and cognitive disabilities in the criminal justice system. ADHC has been a partner in that and a number of nested studies. I have also just been given funding by the Commonwealth Government for another major project in which ADHC is a partner. It involves indigenous Australians with mental health and cognitive disability in the criminal justice system. I am also on the ministerial advisory committee for ADHC for families with a member with a disability. I have had a fair bit of connection one way or the other.

CHAIR: Thank you very much for that.

The Hon. MARIE FICARRA: You referred to pilot studies with three agencies and policy recommendations that you made. Can you give a brief overview of the major thrust of those recommendations?

Dr BALDRY: The outcome of those studies was that this intensive support approach did not solve everything, but it did result in a very significant drop in the potential for child abuse. However, the study indicated, not only immediately but over a longer period—it was a short longitudinal study; it went on for a year after the intervention—that the families afforded this kind of support fared a lot better than they had prior to it in terms of the safety of their children. It did not relate only to their children with a disability. One of the very interesting things about the study was that often for those families it was not necessarily the child with a disability who was the possible focus of child abuse. It tended to involve neglect or physical abuse, not so much sexual abuse—although that was certainly a possibility in some cases. It also involved siblings. The study looked at the whole family and the stress on the parents of supporting a child with a disability or children with a disability in the context of that family.

The results were very encouraging with regard to the benefit of this approach. As I said, it by no means solved everything. However, it was one way to provide support to families and to keep those children safe. All of the families we worked with had a child who was likely to be removed. They were families at the critical end of the study and they were all engaged in some way with ADHC services through one of those disability groups. We presented the findings to ADHC and it undertook more research and inquiries and subsequently rolled out across the State a series of intensive family support programs. I was the chief investigator, but I have not done most of the work. Dr Jan Breckenridge has been the key person following through the evaluation of that bigger roll out and she has been coming up with virtually the same findings; that is, that the potential is to keep children much safer.

ADHC was very responsive and it was willing to look at a new or different way of working based on evidence from the evaluations. The component organisations were also very open to having feedback about what worked and what did not. Some things were not working and we were feeding that back to them and assisting them to change some of the things they were doing. That experience indicated to me that at least that section of ADHC was interested in ensuring that children were safe—that was a primary concern—and that it was willing to look at changing some of the things it was doing based on good evidence.

The Hon. MARIE FICARRA: That is very encouraging. You have been looking recently at the criminal justice system and you made reference to that in your submission to this inquiry. One issue you have identified is the lack of suitable accommodation for people with disabilities. What type of accommodation and support do you believe is required? What sort of resourcing and policy direction will we need in the future?

Dr BALDRY: ADHC has been piloting two programs. As far as I can see, the Community Justice Program [CJP] and the Integrated Services Program [ISP] are very good models. ADHC has not had a chance to evaluate them fully, but we are assisting them in looking at the impact of those two very small pilot programs. Is the Committee aware of what they entail or should I explained a little about them?

CHAIR: Yes, please.

Dr BALDRY: The Community Justice Program is a post-release supported housing program—secure if necessary—funded by ADHC for people coming out of prison who have an intellectual disability. It is has been operational for only three years. The final capacity will be for 200 people, and I think it involves 120 now. The intention is to capture—if you will excuse the term, because they have just been released—people who have been in prison a number of times. They are looking particularly at recidivists; that is, people who in the past do not appear to have been able to find accommodation or to be supported in a useful way that meant they did not reoffend. There are a number of services with this approach. It is clearly intensive 24-hour support that is needed. Some housing has to be reasonably secure, but so far it is looking as if the group that is going into the support program is not offending at the rate that they did before. They are being gradually supported to gain stronger living skills and to be beneficial for their wellbeing as well as the community.

The Integrated Services Program [ISP] is a very interesting one; it is much smaller. It is also funded by ADHC. It is not only and not primarily for people coming out of prison, or people in the criminal justice system, but it has serviced a lot of those people because it is particularly for people who have complex needs. By "complex needs" I mean people who have not only a cognitive disability of some sort but also another form of disability in some form, such as a mental health disorder and/or another health problem, such as drug and alcohol. This group of people, certainly in all the work I have done over many years in prisons, has the greatest difficulty in getting services, being maintained in services, staying out of the criminal justice system and being supported in some way to maintain a reasonable life.

The ISP addresses that group, and that is a very important group to address. From my point of view it is very interesting that ADHC is doing that, because it covers the borderline as well as others. The reason that ADHC picked that up is that it is quite clear from my research and the research of others that a straight or a plain intellectual disability, someone who has an under-70 IQ, and associated issues, is actually a lot easier to support than someone who has a raft of issues that compound each other, particularly those who have a borderline intellectual disability. This is a really welcome innovation by ADHC.

CHAIR: You indicated that the capacity of the centre was 200, it is now up to 120. In your background paper you indicated that there is 79 or 80 per cent recidivism and that there had been an improvement. After three years are you able to give a percentage of that?

Dr BALDRY: I have seen only the raw data on that, the final word has not come in. It is looking as if it is down to about 20 per cent going back into prison, comparatively. You asked what kind of accommodation and support: there is a range that is needed. Some people do not require 24-hour secure support, so this needs to be a case-managed approach rather than everyone going into the same kind of accommodation and getting the same sort of service. The approach that is needed, and this is, if I understand it properly, the approach that those two services are providing, and it is an approach which I have recommended for 15 years since I have been working on homelessness and the criminal justice system and people with disability.

An individual assessment is needed and there needs to be a capacity for whoever is managing that case, or whoever the case manager is, to have buy-in from the other services that are needed. All these people need services from other groups. Many of them will need a service from mental illness, the Mental Health Service; many will need rehabilitation for drug and alcohol problems; many will need ordinary health services. This group has significantly poorer health than other people. For example, dental health is a severe problem for this group.

Many will have other sorts of disabilities as well; it may be a physical disability or some other chronic issue. The buy-in is actually the crucial point, because if the other services do not come in and support that person then that is a hole through which often the person will slip.

CHAIR: In best practice, individual case management, probably not too many people would argue with that. What is the cost imperative of that? Has there been discussion on implementation issues? I assume people just did not sit around and say, "Yes, we want world's best practice"?

Dr BALDRY: No. We have not done enough work on that; I mean society and researchers and government departments have not done enough work on that. We need to look at the comparison of what happens when you do not do that. We do not have that information yet. I have just got another grant from the Federal Department of Families, Housing, Community Services and Indigenous Affairs [FaCHSIA] on a homelessness project, in which I am trying to cost the life-long pathways of that group of people on my current study. That would give us a much clearer picture of what it actually costs our society and costs those people, in particular costs of services for someone with an intellectual borderline complex needs disability from the earliest we can pick them up in our services, that might be when they are very small children, with Community Services—for example they might have gone into care—through education and so on.

I will hazard a guess that the outcome of that is going to be quite staggering, because what we find with this group is that, particularly in what one might call the more-negative service area—that is, the criminal justice area and the punitive area or the secure area of services—they cost an enormous amount, because we do not intervene early enough or we do not provide the kind of support that would mean that they do not end up going down that track into every one of those services. In my study there are people who have had 100 interventions with police and 35 court appearances by the time they are 30. They have gone through Juvenile Justice and through many foster homes. My response is not very helpful at the moment, because we do not have the information.

From the little bit of information that we have from our studies, out of the maybe 1,400 people with intellectual disability or borderline intellectual disability in the current study, only about 180 people were ADHC clients when we drew the data. That is very surprising, given that there were almost 700 in that group who had an under 70 IQ, but there might be reasons for that, which I am happy to go into if you would like. The key thing is that almost all of those people became ADHC clients only once they went to prison. So there is a group of people who moved through all of those systems without being provided with the kind of service that they might need. After becoming ADHC clients, their offending and their entrance into prison or reoffending dropped significantly. So, a service made a big difference to them.

Dr JOHN KAYE: Can you put a figure on "significantly"?

Dr BALDRY: Yes, it dropped by half.

CHAIR: I assume that a lot of work is being done on transition from the ideal to convincing the bean counters or the bureaucrats within Treasury?

Dr BALDRY: Yes. Part of the reason that I went for further funding was to try to provide evidence. One does not know what comes out, you have to be open to whatever comes out. But I would be extremely surprised if the cost over the long term was not cheaper. It is not going to be a lot cheaper, because this group may require a lot of intensive support. But one of the things that is becoming obvious out of the two pilot projects, and it was obvious out of that earlier project on families with a child with a disability, is that you do not have to keep up that level of intensity for most people forever. For a few you might have to, but for many you can build up capacity with the right kind of supported accommodation and work with people. As a footnote, skilled workers in this area are just so needed and so few. It is a huge area for ADHC to think about how that might be improved. It is a significant problem.

The Hon. TREVOR KHAN: You talked about an improvement in outcomes after people become ADHC clients. When do people who are offending and are imprisoned become an ADHC client?

Dr BALDRY: You mean when could they? Or when do they?

The Hon. TREVOR KHAN: What is current, and what is the appropriate time?

Dr BALDRY: The current is that they are identified in prison. To be fair to New South Wales Corrections, it has a good disability service—well, it is an improving disability service—but one thing it has had for some time is a reasonable assessment. It has quite a good database and it assesses people who have been flagged as being potentially someone with a disability, that service does assess that person. They are flagged by the service and, internally, Corrections. Corrections notifies ADHC and says, "Look, this person is going to be getting out in a month or so. Would you come and assess them for becoming a client of ADHC?" So, there is a huge amount of advocacy going on between the disability section in Corrections and ADHC in an attempt to do that. The ideal would be that they, of course, were picked up in the community, because if they were picked up in the community it may well mean that they would not have gone into prison.

There is a caveat to that and that is that a significant number of these people may well have under-70 IQ because of acquired brain injury. I do not know whether you have heard much about acquired brain injury yet, but acquired brain injury in the criminal justice system is extreme. It is something like 40 per cent of people in the criminal justice system has a mild or medium or severe form. In the severe form it is anything between 9 and 14 per cent of people look as if they have reasonably severe acquired brain injury. If that brain injury was acquired before they were 18 they may well then need to come under an intellectual disability service from ADHC. But this group is so fussy because they are likely not to be picked up.

It seems to me that what we need to be doing is at either early childhood or primary school ensuring that kids who are on the radar at school as having behaviour problems, as being very difficult to manage, as being disruptive and as not getting on with their school work, they really need to be picked up at that point. What we are certainly seeing with the group that we have looked at, virtually all of them have been either expelled from school or certainly have not finished school. They have not finished even year 9. There is something that is going on there, which is not meaning that they are being identified at a reasonable point but they clearly had a disability during their schooling because of those outcomes and the other things we are seeing going along with that. Nevertheless, some of them may not have acquired their brain injury until after they are 18. That is a much more difficult group to then expect ADHC to have picked up.

The Hon. TREVOR KHAN: In relation to young people who have been through the Juvenile Justice system rather than Corrective Services, what is the crossover between ADHC and Juvenile Justice?

Dr BALDRY: There are a number of things that I could mention about this. Of the group that I looked at over one-third had been through Juvenile Justice. You then have a question as to why they were not picked up while they were in Juvenile Justice to become clients of ADHC, because they were not. Making a little bit of an inquiry into that and having talked with a few people about it the comments were, "Quite a few kids are picked up. Therefore, we are not seeing them in the adult corrections system." What I am seeing in my study are those who have in fact slipped through. There could be a number of reasons for that.

The Hon. TREVOR KHAN: It is not a slip when it is one-third?

Dr BALDRY: No, it is not a slip when one-third has ended up in prison, despite the fact that they have a mental health or intellectual disability and most of them complex needs. I am sure you have heard the rate of cognitive disability in the juvenile system is significantly higher than it is in the adult system anyway. Those who do progress through, there may be a number of reasons for that. I personally think there are maybe three or four. I have not mentioned women at all. Of course, women are a very small proportion of the criminal justice system.

The Hon. TREVOR KHAN: But growing at a faster rate.

Dr BALDRY: But growing at a very fast rate comparatively. There are not nearly the number you would expect to be identified as having an intellectual or borderline intellectual disability in the criminal justice system. People in Corrections say to me they think that is not because they do not have it, it is because it is masked by so many other things. Women on the whole who come into the criminal justice system into prison but also into police custody and so on tend to have a much higher rate of trauma, a higher rate of complex needs and a higher rate of very difficult behaviour, a sort of severe personality disorder. It is really important to recognise that personality disorder is a mental illness. It is not just something that people have made up to explain things. It is a DSM IV mental illness.

CHAIR: Would you explain that?

Dr BALDRY: Diagnostic Service Manual IV, which is the fourth version of the Diagnostic Service Manual for mental illnesses. The issue is that they are not being identified because so many other things are masking their issues. Another reason why they are slipping through from Juvenile is that a very large number are indigenous. Our understanding of indigenous cognitive disability is extraordinarily poor. We need to do an enormous amount of more work on understanding what is happening for indigenous people who appear to have cognitive disability. They may not. I am sure many of you have heard that there still is, certainly there used to be, a very high rate of otitis media in indigenous children. Otitis media often leads to mild or moderate hearing impairment, which then means they can look as if they are not intelligent in school. That is just one factor that one can add into thinking about what is happening for indigenous people who end up in the criminal justice system, or not even in the criminal justice system but who are assessed as having a cognitive impairment. As well as that, there are a range of other issues that we would need to be working with indigenous communities on.

CHAIR: Are you able to take the issue of aboriginal communities further in relation to numbers in the system and rural and regional difficulties?

Dr BALDRY: Yes. I can make two comments about that. One is about the Intensive Family Support services that are being rolled out. When ADHC started to do that, certainly our concern as researchers, our team, but also ADHC's serious concern was: What is an appropriate support service for indigenous families and indigenous communities? There is often a great reluctance by indigenous communities to become embroiled in any form of service which might look as if it might end up taking away their children. So what is an appropriate way forward? There has been some trialling of that, initially in the Intensive Family Support Program. There were very few indigenous families that took it up. They had to ask why. Some of the reasons why were, one, they wanted an indigenous worker, and there are very, very few trained indigenous workers in this field. Two, they were very nervous that really this was a hidden way of assessing that their children needed to be removed. Three, there was a lack of understanding between non-indigenous and indigenous services and the community regarding just what cognitive disability is and how it is supported or not supported in their communities. That is my first comment on that.

If we move to the criminal justice system area, in my research indigenous people have a far greater rate of complex need than other people. That is not to say that other people do not have severe difficulties and problems, but it is increased for indigenous persons in New South Wales in the criminal justice system. That really has to do with a range of complicating factors which means that whereas the average might be two disabilities co-occurring, indigenous people will have three or four or five. There is also the factor that indigenous people in the study had lower educational attainment. That may not be necessarily because they did not have the capacity. It probably had much more to do with the opportunities that they had for schooling. So the move on through has so many factors.

CHAIR: As to assessing the unmet need in the indigenous community, are you able to give any views to assist us in our recommendations in relation to the cost imperative of early intervention for an indigenous person in the criminal justice system? Is there an X factor? Do we need twice the money or three times the money for a case manager? What are we talking about from a bean counter point of view?

Dr BALDRY: It is not only money, by any means. Supporting and training indigenous workers would go a huge way, but ensuring that they are able to work in a way that is culturally competent rather than trying to enforce them into working in a pattern which works for middle-class Sydney. That is not a huge amount of more money. It means, and what we are saying, we need to focus on ensuring that we support more indigenous workers. Equally importantly, training non-indigenous workers who work with indigenous people because indigenous people want everybody to be able to work with them. I did some work quite some years ago with Associate Professor Sue Green, who is an indigenous woman at my university, about the take-up of the services by indigenous communities and their attitude. They were furious that when they went to a service immediately someone found they were indigenous, one, the attitude to them changed, usually in a negative way, but, more importantly, there was an immediate, "You will want to see the indigenous worker", without asking whether they wanted to see the indigenous worker. The impression that many indigenous people that we spoke to had was, "You can't be bothered making sure that you know how to work with us appropriately."

So everybody who works in these systems and who is likely to work with indigenous families and people with a disability needs to have that cultural competence as well. That is not a huge amount of money. I do not think it is even doubling the money. But then there is money that is needed, particularly in terms of accommodation because secure and good accommodation for families with a child with a disability is essential. Many Aboriginal communities do not have good housing and they do not have the kind of support they need to support their children because it is not easy to support a child in that way. I think the money is also needed in schools. There is absolutely no question that we need much better education attention in schools where there are a number of Aboriginal children as to how to work with those children who have a disability in whatever form it happens to be, and for it to be able to be recognised because the signs are not going to be the same necessarily.

CHAIR: Will you provide the Committee with some of Sue Green's papers?

Dr BALDRY: Yes. We have written a paper on that one but I will send it on and I will give you Sue's contact.

The Hon. HELEN WESTWOOD: I refer to young people with borderline or mild intellectual disability not being identified earlier than when they appear in the criminal justice system. Twenty or 30 years ago it was well known that men, particularly young men, with a borderline intellectual disability were much more likely to find themselves in the criminal justice system than their peers without intellectual disability. I also would have thought that with many of the programs that have been funded and implemented and the training that has occurred within our education system that we would be better at identifying children who have an intellectual disability whether it is borderline or more severe. Do you know that they are failing? Do socioeconomic backgrounds make a difference? Are there young people on the north shore of Sydney or in the more affluent parts of Sydney with borderline intellectual disabilities being identified and detected? Does it make a difference in terms of family circumstances, that is, those whose families are less functional or perhaps in some sort of crisis? Do those things make a difference? Do we still have things to learn in relation to them?

Dr BALDRY: Absolutely. There is no question that the group who have a disability that we see coming through into the criminal justice system are from severely disadvantaged places and what you see with families who have access to middle class services and welfare services, of course, they do not end up in the criminal justice system. It does not mean that their experience of disability is for them any less worrisome but they have the capacity to address those things. I think the thing which might be really important to state here is that I certainly come from a critical disability studies approach, and just to let you know what that is, it says that what actually is going on is that someone has an impairment and it is the society which disables; and that by the way we treat people, the way we discriminate against them or the way in which we ignore them or we do not allow for their needs, that in fact we as a society are complicit in making that disability worse for that person—in fact, disabling them in various ways.

Those who live in more disadvantaged suburbs and communities, those who are poor, those who are from marginalised groups in our society experience that disabling at a far greater rate than middle class or wealthier people, there is absolutely no question about that. Now there are many reasons why those people are in those communities. Certainly for Indigenous communities it is 240 years, or whatever, of racism and mistreatment and a lack of attention and respect but for other groupings there are things such as poverty, drug use in the family, family breakdown—all those things are then magnified if there is poverty and disadvantage. If the community in which that family or those people exist does not have capacity to support them, and I think that goes particularly for schools that have a large number of children who come from disadvantaged families and backgrounds, and their capacity to support those children, is much less than a school on the north shore or the eastern suburbs or the inner west where there are a lot more families that are able to support their kids in ways that that might not happen for those children in schools where there are a number with severe issues. So those schools need support and attention.

You commented why, after 20 or 30 years, we are not picking up these children. We certainly are in middle class and wealthier places and there are certainly better services but what is often happening for the children that I am talking about is that they are skipping school, they are not attending school to the extent that they might, their families do not have the wherewithal to take them to places, so they get a referral to go somewhere. Do they go? They might not have the money to or they just might not think that this is an appropriate thing to be doing. They might not be actually able to do that. So even if there might be a referral that does not necessarily mean that the child is going to be supported. We need to do other things. We need to be supportive in other ways.

Dr JOHN KAYE: "We need to do other things" is what this Committee always hears. What do we need to do where some schools have a high concentration of disadvantage—we know where those schools are—

Dr BALDRY: We do.

Dr JOHN KAYE: This State and on and off the Commonwealth has been funding those schools.

Dr BALDRY: Yes.

Dr JOHN KAYE: You are talking about children in families that do not have high levels of functional capacity, and we know about that. You are talking about the failure of those children to get access to services and then you say "We need to do something". The knowledge of the problem is nothing new, it is the "do something". What do we need to do?

Dr BALDRY: The example of the intensive family support that I mentioned earlier is one such example. I think there are many ways to do this so I will name a few. That intensive family support was not only, but was largely, for disadvantaged families. What that ended up doing was supporting those parents to be able to access things that were going to be beneficial for them and it also supported them in a way which said, "Look this is not to your disadvantage" which, of course, many think it will be—to have somebody who they could trust to do that. One of the things which was the most shocking to me in that study was families saying, "I couldn't believe it. We had the same worker for the whole time". Now this was only three months of intensive work and their comments were, "We never see the same person twice" or "We rarely see the same person twice". Now these are people who are with Community Services, ADHC and other services as well. I think that is a really important that those schools need to have workers who work intensively and supportively with those families, not just with the children.

Dr JOHN KAYE: Do you say those workers need to be attached to the school?

Dr BALDRY: That could be a way to do it.

Dr JOHN KAYE: Or at least they need to be accessible to the schools to provide those services.

Dr BALDRY: Yes. I think one of the problems is if we just say, "Well, this comes through ADHC or the Spastic Centre or Northcott workers" how do they get referred to those services? The only place which sees everybody is the school. So if the school in a sense is a hub for that, it does not mean the school has to do it, it means that the school is the place that can make the connection because if we wait and say, "The school counsellor" or someone comes to the school "gives the parent a referral", like I said, that often does not work. If, in fact, there are people there on the spot who are willing and able to work with people, and to work with them in their homes and not say, "You've got to come downtown at 2 o'clock on Monday afternoon for a meeting". Again many of these families either do not have the capacity, they have other small children, they have other issues going on and many of them are in domestic violence as well.

For those families, we have to think differently about the way in which we expect them to take advantage of the service. An example in that earlier work we did was again the mother, in particular, but both parents, if there were both parents, saying, "What was so beneficial about this was that the worker actually came to my house sometimes and actually saw how difficult it was and gave me some practical support." Those are the sorts of things I am talking about. I think we have to think outside the box in that we do not, and should not be expecting that everybody just abides by our expectation that everybody turns up between 9.00 a.m. and 5.00 p.m. and that they turn up at a suburb which might be half an hour away from their home, particularly when they live in the west where every hour or so there is a bus and the transport is expensive and where you cannot get your children minded if you have two other small children and you are taking another child with you. It is fine for middle class people; we can do that, but many others cannot.

The Hon. TREVOR KHAN: Let us think in the box for a second. A pre-condition to a child or young person entering a Juvenile Justice institution is that a Juvenile Justice report is prepared. Has anyone looked at the quality of those Juvenile Justice reports and whether they identify kids, for instance, with intellectual disabilities before they actually drop into the system? If the answer to that is "No", are you aware of what is being done to actually improve the quality of the handwriting at the very least.

Dr BALDRY: I do not know that they do that. I am agnostic on that. I have not ever seen that it is actually done. It would be very beneficial obviously if that were done. I think though there is a question about what would then that mean. Would it mean that they do not go to Juvenile Justice or that they go somewhere else?

The Hon. TREVOR KHAN: What it might mean is that it triggers an earlier involvement of ADHC or the Department of Community Services in assisting the family/child either at the time the child is entering the Juvenile Justice institution which is normally for a short period of time or, alternatively, when the kid gets out.

Dr BALDRY: I think that that is a very good idea and I do not know whether you have heard about another trial, a very small project that Juvenile Justice, Housing and I think it is Catholic Care is running which is JATAC which is the Juvenile assistance program—I will provide the words for you—

The Hon. TREVOR KHAN: No wonder members of the public get confused.

Dr BALDRY: This has been running for quite a long time and there has recently been an evaluation done of this program. It picks up kids—only older kids; we are only talking about the back end of the system—it provides a support worker, it provides accommodation and supported accommodation and it is very highly flexible. In that grouping a very large number of the kids who have gone through that have some form of disability—mental health, cognitive disability, often a combination—and the outcomes of that are proving very successful. On the surface that might look like a lot of work—it is intensive work—but, in fact, it is far cheaper than sending those kids back to juvenile justice, to detention, and it is certainly a lot cheaper than them ending up in the adult system.

CHAIR: There is some scientific evidence on that is there?

Dr BALDRY: Absolutely. Juvenile Justice could provide you with that evaluation.

CHAIR: I think Helen has got some more questions, and John and Greg.

The Hon. HELEN WESTWOOD: I would really like to tease out a bit more what it is we can do to make a difference in terms of identifying and getting services in as early as possible. If we could put some questions on notice and maybe get your thoughts? It seems to me we need a whole-of-government approach. There is no use just ADHC, the Department of Education, Community Justice service all doing their own thing. It also concerns me that unless we have a whole-of-government approach there are bureaucratic changes—this program gets plucked out, budget savings have got to be made. I would like some advice from you about what you think is the absolute necessity that we need in each of these schools that we know it is much more likely that these children are going to be attending and these families will need those services. I know that is a big question but in terms of our recommendations it would be wonderful for us to come up with something that provides a very practical answer to this really serious issue that you have been researching.

The Hon. GREG DONNELLY: Thank you for coming along today and providing some additional evidence. My first question is a general one; forgive me for being a bit naive about it. In terms of trying to understand the issue of mental intellectual disability, if we look at society globally, is it stable, is it growing, is it recessing? Can you give us a global overview of the whole issue? I know, once again, it is a very broad question, but could you just give us a sort of global general explanation?

Dr BALDRY: Children who are born with intellectual disability, that remains reasonably stable. You can certainly support and improve their capacity with education, support and a whole range of things. There is evidence that IQ can be raised to some extent, but intellectual disability if identified in a young child is usually a reasonably stable thing through that person's life.

The Hon. GREG DONNELLY: And over time in the general population—

Dr BALDRY: Over time it is fairly stable as well. Where the changes come are things like acquired brain injury. There are times when there is a much higher rate of acquired brain injury—times of war—and some communities suffer much higher rates of acquired brain injury. Acquired brain injury not only before prison but in prison is not that uncommon because sometimes there is violence in prison, but that group of people is often, when they are out of prison, involved in violent behaviour. A very common form of acquired brain injury is via abuse of alcohol and drugs. So those sorts of things vary over time and vary depending on what the nature of the society is.

The Hon. TREVOR KHAN: Or groups within the society.

Dr BALDRY: And groups within the society. Prior to 1788 Aboriginal people did not get acquired brain injury from anything we brought along, so absolutely. Mental illness and mental health disorders are very different things from borderline intellectual disability or acquired brain injury, because those things are relatively stable. Mental illness is usually episodic and it may be that someone only has one episode or it may be that they have a chronic mental health problem throughout their life. The rate of mental illness in societies is generally thought to be relatively stable. For example, schizophrenia is thought across the world to be a very small percentage but a fairly stable percentage, and the same with other psychotic things, and bipolar and so on.

Dr JOHN KAYE: Like autism?

Dr BALDRY: There are other sorts of disabilities such as autism which seem to vary. I am not an expert in autism at all so somebody else might answer that question. But as far as an area which I think we have not really got a hold of well yet is that the sum of the parts for someone who has two or three disabilities together is much greater by a long way than just the individual things added together. That is what you see turning up in the results that I look at, that if someone just has a mental illness, just has schizophrenia—I am not saying "just" in the sense that it does not matter, I am saying only one thing: just, say, schizophrenia or just bipolar or just clinical depression—those people do not have nearly the kind of disadvantageous circumstances around them than somebody who has one of those plus has, say, borderline intellectual disability and a drug and/or alcohol—and often both—issue, because the combination, the accumulation of those things means a huge number of things in their lives fall out: school falls out, work falls out—they probably do not ever get to have stable work at all—housing falls out; their families often cannot cope with them. That level we do not know very well because it has never really been measured well before and my guess would be that with the increase in drug and alcohol use, particularly drug use, over the last 30 years there might have been an increase in that complexity. Certainly for the indigenous community that is a sleeping, terrible problem.

CHAIR: Unfortunately, you might have to take the rest of the questions on notice. You have been extremely helpful to the Committee this morning. Your being here with us has been greatly appreciated. We thank you for your expertise.

(The witness withdrew)

(Short adjournment)

CAROL GAYE BERRY, Executive Director, NSW Council for Intellectual Disability, Level 1, 418A Elizabeth Street, Surry Hills, affirmed and examined:

CHAIR: Would you like to make some opening remarks before proceeding to questions?

Ms BERRY: Yes, I would. First of all I thank the Committee for the opportunity to address this important inquiry. As mentioned, I represent the NSW Council for Intellectual Disability; we are the peak body representing the rights and interests of people with intellectual disability in this State. People with intellectual disability are not simply actively involved in our work but drive the work that we do. Our constitution stipulates that our board must be made up with a majority of people with intellectual disability.

In my opening comments I will try and address the key issues, as I understand them, which the Committee has been particularly interested in during this inquiry in terms of oral submissions. I will try and contain my comments to a few of what I perceive to be as the key issues. I think Jim Moore, the Chief Executive of ADHC, put it very well when he addressed this inquiry and said:

> We know we have made a very substantial difference to the lives of a large number of people with disability and their families. We are also well aware of the need to do a lot more, both in terms of our own performance and in terms of being able to do additional services.

I think that very well encapsulates our perception of the situation. As the Committee has already been made aware, at the present time it is quite challenging to gauge what level of unmet need there is out there. There is some data but it is not conclusive. We certainly receive many calls to our service about it. For example, many people feel they are in crisis and need more help but feel they have nowhere to turn. These people may already be receiving assistance from ADHC but do not feel it is enough, or they feel that the department cannot respond to their need. Others do not qualify and feel they have nowhere to go. Unmet need from our experience reflects the generally accepted view that exists across-the-board from respite to accommodation, to day programs, to family support services, behavioural support services, employment services—you name it. However, as Jim also pointed out, the department at the moment feels it must do its best with the limited data available to it and I think this situation needs to be addressed.

If there was greater clarity around assessing actual need this would go a long way not only towards the department's own planning processes but also the perception that the government was responding to actual need and assessed need. At the moment, as some people who have appeared before the Committee have already observed, the system seems to be driven by crisis. It is crisis responsive and this immediately places everybody on the back foot. Data would help assist with the feeling that we are helping a certain number of individuals and their families in particular ways but we know that there is a whole ocean of need out there and we have not even started to touch the sides. Information and responsive resourcing may be the way forward here.

In our view there is a clear and pressing need for the department to become more client focused and client friendly. People constantly report—both service uses and service providers—that they are frustrated by a lack of transparency in the department, a lack of clear information, that there is too much red tape, paperwork, activities and process that rather than enhancing services and enabling people actually frustrates them. I think the department would benefit enormously from some form of systems overhaul or audit to assess where they can be more enabling rather than frustrating to clients, families and services alike.

On this point of enabling people with disability, further progress needs to be made within ADHC on this very subject. Innovations in this area do not match, in my view, the department's objectives or rhetoric. In my humble opinion the department, as well as the State Government more broadly, is yet to make an all-important paradigm shift when it comes to being enablers of people with disability. I know that is a broad comment and I am quite happy to be challenged on it. If I may quote Mr Moore again on the subject of enabling people with disability—and this is the final quote I will be making of Mr Moore's—he said:

> That is an area where when you look it from both a program administration perspective and also from areas like looking at it from the Human Rights United Nations Convention, which talks about enabling people with a disability to be in control of their lives, we need to change our administration quite substantially.

I would agree entirely with that assessment. In terms of a paradigm shift there is a pressing need for government and relevant decision-makers to enable people with disability and their families to be in control, to be at the centre, rather than people with disability and their families feeling they are passive and often frustrated recipients of services.

Discrimination broadly is still a major problem for people with intellectual disability and for people with disabilities more generally. We must acknowledge the damaging repercussions of making people with disability feel different, like outsiders, people for whom things should be done, rather than equal citizens with rights not only to participate but to receive the right supports in order to participate. This does not mean that the community purely shoulders this responsibility; government has a crucial role to play in providing these supports. Mr Moore's department has a critical role to play in the provision of what is required to assist people with disability to live full and fulfilling lives.

Across Australia there is an increasing emphasis on the rights of people with disability and the importance of person-centred approaches to the development and delivery of service responses. Some jurisdictions have recently revised their disability services legislation to further emphasise the rights of people with disability and their place at the centre of service provision. There are a few key pieces of legislation in particular: the Disability Services Act in Western Australia, the Disability Services Act in Queensland, and the Disability Act in Victoria. I think it is no accident that these jurisdictions that are probably the more innovative; namely, Victoria, Western Australia and Queensland, have amended the legislation in order to further rights objectives. This would be a very welcome development in New South Wales. Many jurisdictions are implementing reforms to make their service systems more person-centred, and many have developed key policy and strategy documents that reflect this focus on the individual. There are numerous examples of this that I can provide if the Committee would like further information on this subject.

Finally, consistent with the promotion of human rights and the principles of participation and self-determination across Australia, people with disability and their families and carers are playing an increasing role in the design and delivery of support programs and services at a local level. There is a move towards tailoring service provision to the individual with a range of models focused on supporting the person with disability to live in the community. There is an emphasis on supporting and strengthening the capacity of families and developing informal support networks. Associated with the emphasis on individually tailored responses, there is an emerging trend towards directing people with disability and their families to supports from a range of human services at an early stage in order to reduce, delay or avoid the need for more intensive supports provided by the specialist disability service system.

The Hon. GREG DONNELLY: Can you describe intellectual disability so we have a clear picture in our minds?

Ms BERRY: It is our understanding, and we can only estimate, that approximately 100,000 people are affected by intellectual disability in New South Wales. The general view of assessing intellectual disability is that there are two indicators. The first is an IQ assessment, so it is a person who has an IQ below 70. People who have an IQ below 80 would be considered borderline. There is also an assessment of functional skills, if you like—a person's capacity to have the skills set that they require in order to assist them with daily living. They are really the two indicators that are looked at to indicate intellectual disability.

The Hon. GREG DONNELLY: Where does that figure of approximately 100,000 come from?

Ms BERRY: Unfortunately there is not clear data but there is a general understanding that intellectual disability affects about 1 per cent of the population. We can only extrapolate from the general data available. There is not clear information.

The Hon. GREG DONNELLY: So, 100,000 is a best estimate number?

Ms BERRY: Yes, around 300,000 nationally.

The Hon. GREG DONNELLY: I listened to your comments about trying to grasp the level of unmet need and I was a little unsure of what you were saying. On the one hand I got the impression there was a view that there was some unmet need out there—

Ms BERRY: This is based on my submission?

The Hon. GREG DONNELLY: Yes. Then you went on to say in your presentation that there is an ocean of need, a huge amount. Can you explain that so we can grasp the size and dimension of the problem?

Ms BERRY: I am not specifically referring to people with intellectual disability and their need when it comes to unmet need in the community; I am speaking more generally about the DADHC-type population. People with intellectual disability represent about 55 per cent of DADHC's client base, so they are a majority. I used the expression "an ocean of need" because I think sometimes there is a sense of an overwhelming need in the community by people with disability and their families. Some of the data certainly suggests that. For example, if you look at the report produced by the Australian Institute of Health and Welfare in 2007 in regard to supported accommodation some fairly large statistics came out of that survey. It certainly would not be over-dramatising the situation to say that there is great need in the community. Our capacity to accurately assess that—I certainly did not want to give any indication that the level of unmet need is mild, because I do not think it is; there is a real need. However, we do not have any accurate data to be able to say, "This is the number of places we need. How can the Government respond to that to not only assess but also address it?"

The Hon. GREG DONNELLY: That brings me to the next question, which relates to your thoughts and reflections on what tools Government needs to use, either new tools or refinements of old ones, to get a clearer understanding about need. It seems to me it is critical from a public policy point of view to try to fully comprehend the dimensions of the issue and the policies to follow that arise from that. What tools are we missing in relation to the data?

Ms BERRY: One of the observations made in the Australian Institute of Health and Welfare report is that they extrapolated from waiting list information and information currently being gathered by State departments. Certainly there is room in New South Wales for more comprehensive data collection and more transparent use of that information. At the moment notions of waiting lists seem a little ad hoc within the department. For example, they can cite certain figures so there are clearly some lists relating to need for accommodation. Some of the evidence that was presented was that there were about 700 families really needing accommodation immediately and another 1,000 families less urgently, so obviously some information is being gathered. But I do not think there is consistent information throughout the States and Territories either and that is one of the things the Federal Government has identified. They are hoping to find a better way of assessing unmet need nationally. My understanding is that the New South Wales Government has responsibility for developing that at the moment, which they are working on, and I think that was mentioned in evidence. There is other information available and I would be more than happy to point the Committee in that direction, certainly to what I have read.

In thinking about better data collection and how you would go about getting that my mind can only extend to waiting lists. Potentially there is room for more detailed consultations with current service users, but of course that does not necessarily mean you are going into the community to find out who you are missing. DADHC engaged Allens Consulting to look at the issue of individualised funding and one of the assessments that those consultants undertook was a series of case studies. They engaged with a certain number of families—I do not know the exact figure so I should not attempt to cite it—but those case studies were quite detailed. They looked both at DADHC clients and people who were not DADHC clients and how needs were being addressed, how effective it was, and the satisfaction levels.

On top of waiting list information there is room for the department to be more proactive, whether they do the work themselves or engage others, to get a sense of some of the need in the community. I imagine some of these issues are currently being considered by the State Government because they are doing that work for the Federal Government. I know that the Australian Bureau of Statistics released a report yesterday about how they pick up survey data about disability from the general population and the report mentioned the difficulties of getting accurate information about disability and need. There is obviously going to be continual tweaking in order to get more accurate data over time, but it is a vexed issue and there is no simple answer.

The Hon. GREG DONNELLY: You spoke towards the end of your presentation about the importance of looking ahead to individually tailored responses to deal with people with disability. When one thinks of individualised responses or personalised responses to deal with matters, generally speaking that often conjures up the notion that it will be more expensive because it is almost an individual exercise, a bespoke process of creating something for the individual, and almost by definition that is going to cost more and take more resources. Obviously you are pushing uphill in some respects in trying to persuade a government to do that because you are really asking for a bigger piece of the pie. That approach, though, is likely to have savings effects elsewhere, so the initial thought that it will be more costly to approach it in this way as a strategy may well be misleading because all the other things that would be costly are not taken into account. Is there any way of conceptualising how an individualised tailored approach, which on the face of it may be more expensive—few would argue it is not in the best interests of people to do it this way—would enable government to derive savings from it?

Ms BERRY: There has been quite substantial research undertaken in this area, which indicates you are exactly right, there are cost savings that arise over time because, for example, people use their money more efficiently and service providers use their money more efficiently as well. The Social Policy Research Centre, which I referred to in our submission, recently released a report that was commissioned by FACHSIA that goes into great detail about individualised funding and some of the effects. That is a very rigorous study and I am certain that some of the more specific figures that prove this point would have been assessed in that report. I am certainly happy to highlight that and bring the relevent section of that report to your attention. There is also other research that has been undertaken internationally that shows cost savings over time.

Once you have the right model of assessing need at the beginning of the process and you had, for example, the right assessment tool to assess a person's needs and a way to match a dollar figure against those needs, if that was a consistent tool you could utilise as well as a consistent person-centred planning process that enabled the development of a relevant individual plan, and you had both those models down pat, that would be quite efficient. You would then also get a benefit in terms of client satisfaction. Almost across the board families are indicating they would like more flexibility from the department in New South Wales so that service is more responsive to individual families' needs. Both the service sector and families have identified that as something they would like to see in Stronger Together phase 2. I think there will definitely be a trend in that direction anyway. To answer your specific question on cost savings, there was evidence to indicate that. I am sorry I cannot cite it to you now.

The Hon. GREG DONNELLY: That is fine. Perhaps you could highlight them for us.

CHAIR: Can you elaborate further on the issue of efficiency, flexibility and client-centred service, because I do not doubt that when the studies are done they will find there are two sides to the coin? Definitions can be very nebulous. Depending on where you are coming from it may be efficient if you are the client but the definition of efficient may be different if you are the service provider or the funder. Are there concerns within the user community, and maybe even the service provider community, that the definition of "efficient" may be muddied by quality and who defines "quality" and "efficient"?

Ms BERRY: A report finalised in June 2010 was relevant to the Government's Industry Development Fund. That report is about future directions for service provision in New South Wales. It was commissioned by the department but developed by NDS and KPMG. They first consulted quite broadly with the service sector. Industry has indicated itself that it would like to go more toward person-centred outcomes. There is a desire within the community of service providers that the Government move in this direction as well.

CHAIR: I assume that would be self evident.

Ms BERRY: Yes. I suppose there must be some recognition in that that flexibility, quality and efficiency—the key words to which you are referring—

CHAIR: I am suggesting those words are very nebulous in their definition depending on the eyes of the beholder, whether I am a funder or a user. I can define that word very flexibly. I assume that Treasury and the bean counters would define "efficient" as the least costly.

Ms BERRY: Yes.

CHAIR: The user may have a different definition of "quality" and "efficiency". Have those dilemmas or dichotomies been thought through by the users when they are presenting the very important and rather self-evident issue of their being the centre? I am referring to the people using the service and the need for flexibility and personalised services. I take that as a given.

Ms BERRY: Yes.

CHAIR: However, I am concerned about who is defining the words.

Ms BERRY: It is difficult for me because I certainly do not come at the issue from the Treasury perspective. However, having said that, it is clear to me from what I have read that the New South Wales Government is concerned about the increasing numbers of people and the increasing level of need in this area, both when it comes to both ageing and disability. I would imagine that it is perceived to be a potential budgetary black hole.

CHAIR: Not if they have a flexible, innovative definition of quality and service.

Ms BERRY: Pardon my expression, but I think everyone wants bang for their buck in terms of the funding dollar being utilised in a way that promotes client satisfaction. That must be an indicator in itself. Ultimately the Government is interested in ensuring that its initiatives are popular and get good feedback from service users about quality service. Satisfaction is to be sought after in terms of service users, but ultimately Treasury and service users have the same objective, which is quality and flexibility. I am not entirely sure what you are getting at.

CHAIR: I am merely saying that you might find there is a multitude of definitions of the nebulous words that you use. You might find that Treasury has a slightly different definition from that of the user. It depends on whether I want x cost or x minus three cost.

Ms BERRY: Sure.

CHAIR: You need to have a strong, consistent definition of those words to ensure that both parties—the funder and the user—are speaking the same language.

Ms BERRY: At the end of the day I suppose they would be.

CHAIR: Hopefully you are right.

Dr JOHN KAYE: Thank you for your submission; it was very enlightening. I must admit that I was surprised to hear—I thought these days were gone—that there are approximately 1,400 people still living in large residential facilities.

Ms BERRY: That is right.

Dr JOHN KAYE: I think most people thought they had disappeared as a result of the Richmond report two decades ago. There is a suggestion—although I do not think the Committee is aware of it—that the Government is redeveloping those facilities. What is your understanding of what the Government is doing with those facilities? I assume you think it is the wrong thing to do.

Ms BERRY: That is right. This figure is fluid, but there are approximately 1,400 people living in large institutional or residential centres in New South Wales. Some of those facilities are directly operated by ADHC and some by non-government organisations. The larger facilities tend to be operated directly by ADHC and as a general rule the smaller facilities are operated by non-government organisations.

Dr JOHN KAYE: What numbers are you talking about?

Ms BERRY: A large residential centre accommodates more than 20 people. Obviously there is diversity in the numbers ranging from Stockton up north, which has approximately 450 people living on the one site, compared with other large residential centres that have a little more than 20 living on the one site. There is some disparity or difference in the numbers. However, the rule remains the same that where larger groups of people are living together in one setting there is an inevitable compromise with regard to the individual outcomes that can be achieved. That point was emphasised in New South Wales Ombudsman's report released in 2009, which looked specifically at individual planning and outcomes that could be achieved in ADHC-operated large residential centres. That was a comprehensive report and its conclusions were clear that the model could not deliver for individuals. That is a problem.

Dr JOHN KAYE: No matter how good the model was, it was not going to be able to deliver?

Ms BERRY: They certainly raised some questions and looked at the relevant legislation. They were clear in their conclusions that there were very pertinent questions to be raised about whether the model could deliver. That is a concern. From a broader perspective, there has been an international trend to move from congregate settings for people with a disability to smaller more individual settings. There is a recognition that grouping people together just because they have a disability and housing them in one location is not perhaps the best outcome and that from a fundamental rights perspective we should be shifting towards more individualised outcomes. We are not talking about units but people with real needs and a real right to be able to engage in community life. That is the broad debate.

The New South Wales Government has previously committed to closing large residential centres. However, progress has been stalled. The Government did announce some years ago that it intended to redevelop large residential centres rather than devolve them. That process is currently underway. It is an issue of some controversy within the sector and it continues to be a live debate—that is, the appropriateness of that decision.

Dr JOHN KAYE: Your organisation would oppose the redevelopment of those centres. Is it fair to say that the majority of organisations representing and supporting people with intellectual and physical disabilities would oppose the redevelopment of those sites?

Ms BERRY: The peak advocacy organisations would.

Dr JOHN KAYE: Of course, the alternative model is smaller residential arrangements with two or three people cohabiting.

Ms BERRY: That is one possible option. We take that a step further. We feel that ideally people should be supported to live in whatever arrangement they feel is appropriate, just as the rest of us have that right. Most of us do not put our hand up to live with large groups but with a partner, siblings or a friend or two friends. That is the ideal model. People with a disability should have the right to choose who they live with and under what circumstances.

CHAIR: Has any work been done on limited choice and why the transition to smaller institutions has stalled when the Government clearly supports the concept?

Ms BERRY: That is probably a question best asked of the Government. I cannot give you a clear indication why the Government has chosen the redevelopment path rather than sticking with the original commitment to close down those institutions. It would cite a number of reasons, but I am not in a position to give an accurate sense of why it has made that choice.

CHAIR: Is there any anecdotal view within the industry?

Ms BERRY: In some communities where institutions are located families may have expressed reluctance or concerns about their family members being moved into more community-based settings. That is certainly the international experience. A lot of research has been done on this issue. At first families feel concerned and nervous about their loved ones, but with the experience of devolution they become quite robust supporters of the process. Presumably the Government is mindful of the reservations in some communities. I imagine that there is some economic reasoning behind it.

CHAIR: Can you expand on that?

Dr JOHN KAYE: It is cheaper.

Ms BERRY: It might believe it is cheaper. There is some difference of opinion about whether accommodating large groups together in one facility is cheaper. However, that might be the Government's view and the reason it has chosen that path.

CHAIR: I would love to own a Lamborghini, but I cannot afford it. What are the limitations on choice?

Ms BERRY: Do you mean choice for individuals?

CHAIR: I am talking about the choices for individuals. Is there any discussion about the issue of cost?

Ms BERRY: Do you mean the cost comparison of accommodating people in a large setting compared with the alternative? Is that what you mean?

CHAIR: Yes.

Ms BERRY: Research has been done about which option is most cost effective. Once again, that is not the perspective from which I approach this debate, so I am not an expert in that area. However, I have cited some figures in our submission about how much it costs to accommodate somebody in a 24-hour support setting. It is much more costly than supporting someone in their own home. I can point to some evidence in that regard in my submission. In terms of the question about choice, I assume that you mean it is a vexed issue because it comes down to each individual making a choice about where they want to live and how much choice is available to people with a disability to be accommodated in those settings. Is that correct?

CHAIR: It is a given that we all want to maximise choice. I am not suggesting for one moment that we should restrict choice. I am merely saying that there are some limitations as to choices. Has there been any discussion in the community about how far we are able to devolve?

Ms BERRY: I think it purely comes down to the priorities of the government of the day. Many other jurisdictions in Australia have chosen the path of devolution. Many other jurisdictions internationally have chosen the path of devolution. There is no limitation on how much choice you are able to provide to people with disability and how they are accommodated. It comes down to your fundamental philosophical commitment to people with a disability and being able to provide them with accommodation which you consider to be appropriate at a rights level.

CHAIR: That is why I asked the question: the philosophical question has been answered, the Government is supporting devolution, but it has stalled. We are trying to establish why it has stalled.

Ms BERRY: And I have given a couple of what I assume are the reasons, but I am not the Government; therefore, I cannot tell you.

CHAIR: As an operative in the industry I thought you may have a view.

Ms BERRY: I cannot get my head around it myself, I have to confess.

CHAIR: Am I right in suggesting that it is a fairly fundamental issue?

Ms BERRY: Yes.

The Hon. HELEN WESTWOOD: Earlier you talked about discrimination. Could you elaborate on where you believe discrimination is most apparent in our community against people with an intellectual disability? What do you think that governments or communities or advocates need to do about it?

Ms BERRY: Given that I work directly with people with intellectual disability and I report to people with intellectual disability on my board, some anecdotal evidence comes to mind in that all the members of our board would be able to express to you quite clearly where they encounter discrimination in their daily lives. That has been a lifelong experience. Where it really is driven home for people with intellectual disability, once they start to understand the level of discrimination which they have encountered, it comes down to your perception of what you are capable of achieving. For people with intellectual disability routinely there are lower expectations placed on them, that is one area.

Also, that has a systemic consequence. Whether you are engaging with the education system, attempting to get a job, wanting to develop further skills in the community, or wanting to participate, at every point you need to push in order to achieve your objective. Discrimination is systemic in the sense that assumptions are still made about the capability and capacity of people with intellectual disability, the depth of their humanity, what they are capable of, what their daily experiences are like. There is a lack of understanding, so that has a flow-on effect.

The Hon. HELEN WESTWOOD: On the issue of accommodation services, I understand that your organisation is a great advocate of community-based accommodation services, whether in a person's home or attendant care. Is there an optimum size in group homes that your organisation advocates?

Ms BERRY: We have been less critical of the group home model than of other models of accommodation. Once again, it comes down to the personalities, the individuals, who have been housed together. You might have a group home with up to five people that functions quite effectively. However, probably numbers is not necessarily the best way to indicate the success of a model in some respects. Where you have a group of personalities housed together who are clashing, or where you have a problem, it would not really matter whether there are 10 or 4 people living there. Where it is not working, it simply does not work. The system needs to have some capacity to address where a home has become dysfunctional, for whatever reason, that there is some relief of that pressure valve. We are increasingly less concerned by numbers in group homes than with really ensuring that it is quality accommodation that suits the individuals who are involved. Certainly, research indicates the smaller the numbers the better the outcome.

The Hon. HELEN WESTWOOD: Earlier you spoke about other jurisdictions, and you gave the examples of Victoria, Western Australia and Queensland, which you believe are more innovative. Generally, why or how is that? Secondly, I am particularly interested to know if they have a different approach to accommodation services and whether those jurisdictions have completely eliminated large residential settings.

Ms BERRY: My understanding is that Victoria is very close to closing almost every large institution in that State. There is some research which I could provide in some detail about where each jurisdiction is up to.

The Hon. HELEN WESTWOOD: Yes, thank you, that would be helpful.

Ms BERRY: In terms of other jurisdictions being more innovative, Western Australia has had a model of local area coordination for some years where they have recognition that support for people with disability and their families best occurs at a local level with local knowledge. If you are talking about enabling families and developing the capacity of families and the community to be more embracing of people with disabilities, it all happens best at the local community level. They have had a model of local area coordination for some time. Recently consultation has been undertaken by ADHC on Stronger Together phase two. One of the clear desires that came through that document is that people would love to see a local area coordination model rolled out in New South Wales. That is one example of the recognition of what is needed in communities and government responding to that.

The Hon. HELEN WESTWOOD: I wonder whether you have enough information to help the Committee with an understanding of the pattern of accommodation needs of people with intellectual disabilities. Obviously a child may need more respite, perhaps attendant care at home depending on whether they have other disabilities, or early intervention programs, and so on. I assume that respite becomes a greater priority and need as they get older, perhaps not. At a certain age are they much more likely to want to live independently in the community rather than at home with their family? Has such a pattern emerged that can help governments plan accommodation services to meet the needs of your community?

Ms BERRY: Whether there is concrete data, which can give you a sense of clear needs at each stage, I would imagine that families' needs would be different, to be honest. So, no, not that I am aware of. There is no clear research about different times in people's lives and what specific supports are more relevant. However, your overarching point is very relevant, in that families do report that at different stages different supports are needed and that does change over time. The ability of the system to respond to that is part of the flexibility that people are looking for, particularly in regard to respite. Yes, that is an ideal model—that we have a more responsive system regarding what families need at different stages of a person's life. We know that our needs change quite substantially over time, particularly as we transition into early adulthood and adulthood.

The Hon. HELEN WESTWOOD: Are you finding that respite care services are perhaps inadequate in placements, or not flexible or responsive enough?

Ms BERRY: Both of those are indicated. There are still families who report that they are not receiving enough respite in order to feel that they can still support the person to live at home. For example, they are starting to consider a supported accommodation option, which is not their ideal. Yes, there is definitely a need and the Government has responded by creating more respite places and there has been a definite move in that direction, which is great. However, there is definitely unmet need in the community both in regard to the flexibility of respite services and also the level that is available.

CHAIR: To expand on that, with flexibility and all the issues that relate to the system being supportive and user centred, I assume that the vast majority of people are supportive of those things. In the mix, how are we addressing the issues of measuring the funding, the skills and training of the workforce, et cetera? On the issue of elderly carers who are concerned about the stability and caring of their children when they are deceased, how is that addressed? How are we marrying and mixing those two strained issues together, as they can cause tension and difficulty with people coming together with the devolution because of all the issues being supported by the vast majority? There is tension because of the various stages that people are at.

Ms BERRY: There are a few different components in your question, which would be tricky for me to answer generally. If I understand correctly, your question is: how is the system dealing with some of the tensions that families experience throughout life transitions? Is that right?

CHAIR: Not only transition by the person with the disability, but those supporting that person such as families and relatives, et cetera?

Ms BERRY: That is probably one of the reasons why the system is characterised as a crisis-driven system. At this stage, you find a lot of families who have experienced quite serious difficulty when they reach a particular stage of their life. You have given the example of elderly parents in particular, and that is the most obvious example. When parents start to reach the end of their lives they experience profound concern about how their loved one will be cared for by the system.

CHAIR: And concern about the change that is uncontrollable and outsider their comfort zone?

Ms BERRY: That is right.

CHAIR: And the difficulties they see ahead for their disabled child?

Ms BERRY: Yes, which is why unmet need in supported accommodation is still of real pressing concern, because you have quite a large cohort of families who are experiencing that very crisis. They have assumed that their loved one will be cared for by the system, and it becomes increasingly clear that there may not be a place available. You are absolutely right. At key points there are points of crisis in the system that I imagine the Government is currently grappling with; how they support elderly carers as their loved one either moves out of the family home or elderly parents pass away and then there is concern around who then takes care of the person with disability.

CHAIR: That is a big concern of the community and the Government regarding dealing with change and devolution, and not being able to be properly instituted and measured, et cetera, even though the philosophy is great. It is not an easy situation to say, "Yes, full steam ahead".

Ms BERRY: In terms of devolution?

CHAIR: All those nebulous words that are being used—flexibility, change. They are very good in one sense but there are complex definitions for those words. One person's definition of "flexibility" is not the same as another person's. Flexibility is good for one person but not so good for another.

Ms BERRY: Sure. The upshot is that as far as the system is able to address the needs of as many people as possible in a way that is to their satisfaction, that is presumably one indicator of a healthy system, a system that is working well. Can we agree on that?

CHAIR: I think we agree. We have the difficulty of implementing the simplistic philosophies at times, one example being the devolution from institutions to living in the community. It is not as easy to implement as many people think, I would imagine.

Ms BERRY: Sure, but it has been undertaken and successfully undertaken in a number of jurisdictions and the complex issues associated with that have been dealt with by governments. I do not think it is an insurmountable challenge. I do not think it is an insurmountable challenge to find some agreement in regard to some of those terms either, whether you are talking about devolution, flexibility or efficiency. In fact, in New

South Wales we are getting closer to having a consistent understanding of what those terms mean, in actual fact, to the point where you have service users, service providers and the government all saying the same thing: they want to achieve these objectives.

CHAIR: I am yet to come to grips with whether the three mean the same thing when they use those words.

Ms BERRY: They may have different intentions and they may have different challenges. But ultimately there is an increasing recognition that everyone is on the same page and everyone wants very similar outcomes. That has been reflected in government documents as well.

The Hon. HELEN WESTWOOD: I want to ask a general question, which is probably a bit self-indulgent. However, I will proceed. I am interested in your view as an advocate in relation to the issue of discrimination. As someone who worked in disability services when the Richmond report came down, I am an absolute supporter of everything that Richmond recommended, which I believe were all implemented. I state my prejudices before I start. When we first tried to establish group homes in Bradbury I recall the objections, the attitudes of discrimination and the fear of group homes being established in local communities. Now, 15, 20 years on, we see exactly the same objections and fears in relation to respite centres or day care centres that may be open from 9 to 5. From the reactions one would think we were going to establish a nuclear reactor or a jail. Some of the comments are quite frightening. Why do you think we still have not changed the attitudes of our fellow citizens towards people with disabilities, particularly people with intellectual disabilities? What do you think we need to do and how do we go about it?

Ms BERRY: Some of the fear that people still feel in regard to people with intellectual disability stems largely from ignorance. Part of the ignorance stems from the fact that we have traditionally segregated people with intellectual disability. Our general communal experience of people with disability is that they have been shut away and we have not developed an understanding, I suppose, of people with intellectual disability as having exactly the same gamut of needs and exactly the same humanity as the rest of us. We have been sheltered, if you like, from experiencing the reality of people with intellectual disability. As a result there is a lack of understanding, a lack of acceptance and a lack of embracing of what people with intellectual disability can add to our community. The more that we are able to engage people with intellectual disability and the more we are able to facilitate their participation in community life, the less you will start to see the fear in discrimination rear its head.

CHAIR: Thank you, Ms Berry, for attending this morning. Your evidence has been very helpful.

(The witness withdrew)

SHARRYN MAREE LLEWELLYN, Regional Manager, The Benevolent Society, Level 4, 7-11 The Avenue, Hurstville, sworn and examined:

BARBARA SQUIRES, General Manager, Ageing, The Benevolent Society, 188 Oxford Street, Paddington, and

KAREN LEE, Senior Manager, Research to Practice, Ageing and Community Care, The Benevolent Society, 180 Oxford Street, Paddington, affirmed and examined:

CHAIR: I thank the General Manager, Regional Manager and Senior Manager of The Benevolent Society for being with us this morning. We greatly appreciate your attendance. Would you tell us in what capacity you appear before us today?

Ms LLEWELLYN: I am Regional Manager for The Benevolent Society.

Ms SQUIRES: My capacity is the General Manager, Ageing, The Benevolent Society.

Ms LEE: My position is the Senior Manager for Research to Practice for Ageing and Community Care at The Benevolent Society.

CHAIR: Would you like to make an opening comment before we proceed to questions?

Ms SQUIRES: Thank you for the opportunity to speak with you and to answer questions. You obviously all have before you the submission that we have prepared. To set the context, as I hope you all know, The Benevolent Society has a long history of service provision, in fact, going back before this Parliament to 1813. We have a long history of working with people who are disadvantaged. Our current experience in Sydney particularly, we work across the lifespan with children, with families, with people with disabilities and with older people. Our work with people with disabilities is part of that, but it is not our primary focus. We would not consider ourselves a disabilities-specific organisation in any sense. Most of our services which support people in their own homes are, in fact, aimed at older people but increasingly in one part of Sydney, which I will speak to in a moment, they do include people with disabilities and, as well, some people with mental illness problems, mental health problems.

I am going to suggest that most of the questions be addressed to Sharryn Llewellyn. Her title of Regional Manager does not help you very much. She is actually responsible for the day-to-day delivery of a whole suite of services in the southern Sydney area and the eastern Sydney area. That includes the South East Sydney Commonwealth Care Respite Centre and Carelink, which numbers among its clients a number of families of people with disabilities, both younger people and older people with disabilities. Of our services funded by Ageing, Disability and Home Care [ADHC] the majority of those services we provide are in the southern Sydney and eastern Sydney areas. They are the areas where we have the most day-to-day experience in terms of people with disabilities and their carers. We realise that ADHC's-funded services include a number of services for older people, which is a lot of our day-to-day business also in northern Sydney, out in Penrith and also in the eastern suburbs. We are also well aware that the Council of Australian Governments [COAG] proposition that the services for older people be transferred to the Commonwealth may, in fact, influence the questions that you wish to address to us. We are assuming that you will particularly want to address people with disabilities. Again, Ms Llewellyn is the appropriate person who brings the wealth of day-to-day experience.

One of the things that we would like to make clear is that although we are a service provider organisation, as an overall organisation our focus is on creating caring and inclusive communities. We always try to work from a focus for the disadvantaged or vulnerable person. What is in their best interests in the context of their entire setting? What will help them in terms of their family and community connections? In our service provision we are very conscious, particularly where there can be difficult issues—and most of the really difficult issues that arise in day-to-day service provision are around, as it were, the boundary issues and capacity issues—of our being able to support people with disabilities. But we would always want to come from a position of working cooperatively with the person, with their family, with the government funding body and with other service providers to keep the focus on the person and what is in their best interests. We do not want to come from a narrow "what is in our best interest", which is a trap that is too easy to fall into with the service providers. We constantly try to keep that much bigger picture. The focus of our submission is our recommendation in relation to ADHC, particularly in terms of its funding, that we would like to see the focus on a flexibility that can help to meet people's needs, preferences and choice. That is what we are offering today, to be able to speak you further about our experience.

CHAIR: We will now proceed to questions.

The Hon. MARIE FICARRA: You talk about joint local planning and data collection to better able meet the needs of local communities. I know that your experience is at the local provider forums in the St George-Sutherland region for this purpose and measuring unmet needs through this model. You have identified four dimensions of unmet need: client groups, types of support, flexibility in service or due to service inflexibility, a result of funding models, a result of difference in funding across regions. Can you elaborate on the statements in your submission and offer suggestions how ADHC could address all those dimensions that you indicate are important?

Ms LLEWELLYN: In terms of the planning processes that work well locally there have been some that have worked well, particularly in the Home and Community Care Program area which is mainly where we work, that is where there is true consultation and communication between all layers involved in the program. So that is consumers, providers themselves, potential providers as well as existing, and it is the government offices who are involved locally and also centrally in delivering planning outcomes and looking at demographics across an area but also across the State. Where it works well is where you get true engagement at all those levels, where consumer forums are held separately to provider forums, for example, and ADHC has done that quite well over recent years in genuinely hearing the voices of different consumer groups within that. Then when you have providers, existing and otherwise, coming together and talking needs and gaps in existing services as well.

Where it does not work so well is where planning focuses more on the gap only and looks at viability of existing services, and does not look at any innovation or new models of services. It does not ask for new providers to perhaps come into the mix and look at what their views might be. It does not link the outcomes or the findings from consumer consultations in with provider consultations in with the data collected centrally, and give a broader view about what that picture might look like. The current planning round that we are in at the moment for HACC services has very much focussed on viability of existing services and it is going through a direct allocation model of funding which is not planning; it is not asking bigger questions about: What do we want the service system to look like? What are clients or consumers really asking for? What is happening for people that are not consumers that are still on the outer waiting for services? What is the role of government in defining some different models or supporting pilots or new things or new ways to look at programs? It is very much about holding the existing providers which does not allow for a lot of change, it does not actually allow for planning.

The Hon. MARIE FICARRA: When you say perhaps meeting the needs of new providers or new suppliers meeting unmet needs or better able to service the existing needs, will you provide examples of any service providers who you think would be relevant?

Ms LLEWELLYN: I can give you an example of probably going about 10 years ago where there was one large provider of in-home supports for domestic assistance and personal care, and then there was a move, I guess pushed in part through local planning responses, that that particular group was holding a lot of resources but also holding a lot of unmet need and not able to respond as flexibly locally as people wanted. It was a deliberate funding strategy at that point in the HACC program to fund smaller providers; to provide more localised support around domestic assistance and in-home personal care, for example. That strategy has worked to a certain extent. It has certainly pulled a lot of people into the system who were sitting on wait-lists or not, if there were wait-lists held, or they responded to local promotion and found out about the services or came in through another program and then were moved across. But we still find ourselves 10 years later with huge amounts of unmet need, and those smaller programs now holding really large waiting lists, and the large original provider still holding a long list, or not, knowing that there is a lot of need out there that is not being met.

So I guess some of it has worked in terms of diversifying the base, bringing in new providers, bringing in their particular ways of working, but there does not seem to be enough resources to go around. So we have built some more infrastructure, we have built additional providers who then have to have their training processes and staffing places, their buildings and all the things that go with running a service. But you may have increased initially the meeting of the demand that was out there but longer term, no.

The Hon. MARIE FICARRA: Are there certain groups—logically we go to people from a non-English speaking background, the Indigenous needs demographics—where there is greater need that continue to suffer?

Ms LLEWELLYN: I think you have targeted most of those in your question. Indigenous communities continue to be extremely under-represented in the services. They do not tend to want to be located within the mainstream services and the targeted services that are put in place are often poorly supported within the system. They may lack infrastructure or initial expertise in the set up, they may lack staff, they may lack administrative expertise as well, and there does not seem to always be a clear answer from the funder or from the organisations around them to give any kind of support around that. So they kind of tend to struggle quite a bit in terms of being able to meet the needs of their community. In terms of core communities, non-English speaking background communities, that does vary. There are some very strong providers in HACC, in particular, that are very clear about meeting the needs of their community and do it extremely well.

Our services link in very well with migrant resource centres and with core specific services, whether that be a respite service or a social support service, those links happen very well. But within that group, because it is not a homogenous group there are groups within, for example, emerging communities, refugee communities, very small communities that have not actually found their way into the system as yet and there is not material and promotion or conversations that happen with those groups to find out what their needs might be. They tend to get lost in that larger group.

The Hon. MARIE FICARRA: Is there a difficulty to attract the right sort of employees with the skill-sets to work well and understand those Indigenous communities or recently arrived migrants?

Ms LLEWELLYN: It can be. Again it is about capacity building that needs to happen with Indigenous organisations. I think because they are funded in the same way as a non-Indigenous organisation, "Here's your funding. Here's your hat. What's your hurry?" without necessarily the support that needs to go alongside that in terms of building organisational skills, in terms of having a management committee structure in place, in terms of having consumer involvement, policies and all those sorts of things tend to get forgotten so the capacity building aspects that they excel at, sometimes get lost because they are so busy focussing on just surviving as an organisation. So for me it is hard to measure how effective that is but I think we would be hopeful that that would work better if they had that back-up in the community and through the funding bodies.

The Hon. TREVOR KHAN: In an earlier hearing we heard about the size of various organisations and their interaction within the system. How many people are employed by the Benevolent Society?

Ms SQUIRES: It is around about 800 full-time equivalents. Obviously because a number of people work part-time and in some areas may be casual, there are many more individuals but 800-plus, and about 600 volunteers. Some of the snapshot is in our submission in terms of our funding level. We are probably what people might regard as one of the larger medium-size organisations. We are not massive but we are a decent size.

The Hon. TREVOR KHAN: Where do you see yourself as an organisation in terms of the various programs and the like? How many programs would you have been funded for at any particular time?

Ms SQUIRES: By ADHC?

The Hon. TREVOR KHAN: We will start with ADHC.

Ms SQUIRES: If we talk in general it is something like 120 programs over the whole organisation because we operate across New South Wales and also now in south-east Queensland, and one aspect, Social Leadership, now operates in Melbourne so we are incredibly diverse in our focus. If we are just talking around our ADHC funded services they are the ones that are primarily—of our roughly $60 million of funding a year, or income a year, about $5 million of that is from ADHC. The bulk of that primarily is in the southern Sydney area and the eastern Sydney area for which Ms Llewellyn has the operational responsibility. A small amount in the northern beaches area is ADHC funded—that is basically domestic assistance and a food service which is primarily for older people. So the amount of disability-specific funding that we have is actually quite small. However, a program like Southern Sydney Care and Respite, which is the largest carer respite centre in Australia, while it is Commonwealth funded a number of people for whom respite is obviously hugely significant, are carers of people with a disability. So the edges are quite blurry around that but we would never claim to be a disability-specific organisation. We bring a bigger, wider perspective, I think I would say.

The Hon. TREVOR KHAN: Of the programs that you operate are you able to give an indication as to how long the funding cycle is for those programs? You can restrict your answer to ADHC if you like or talk about it in a more general sense if there is not a difference?

Ms LLEWELLYN: For our ADHC programs they tend to be ongoing funding, so it is recurrent ongoing funding. Our Commonwealth funded programs vary between one year and three years.

The Hon. TREVOR KHAN: I refer to ADHC funding which is recurrent?

Ms LLEWELLYN: That is correct.

The Hon. TREVOR KHAN: One issue that has arisen is the lack of data with regards to issues of unmet need and the like. If I accept that then I suppose I draw the conclusion you actually do not tell ADHC terribly much in terms of what you do and what are your waiting lists like? Is that a fair conclusion to draw that you are not providing any data to it?

Ms LLEWELLYN: Perhaps not. Perhaps it is more about the types of data that we are asked to provide and it is probably a difference between the Commonwealth programs and the State programs that we operate. With our ADHC funded programs, it is a State monitored program I suppose, the types of data that we talked about in our submission were mainly around outputs, based on numbers of hours or numbers of individual clients seen. There is no other mechanism within the current funding agreements with ADHC for us to tell them more. They do not ask about stories around clients. They do not ask about unmet need through the reporting mechanisms of the funding agreement. The place where we can have that voice and give that input is through the planning process where that happens at a regional level. So services are asked, "What is your unmet need? What is your waiting list like?"

The difficulty there is that we do not have agreement about what is a waiting list across programs, across service providers so my waiting list is your "cannot provide service" and no record kept. So we have services that keep very diligent wait lists, as we do. We have 120 families on our respite program alone waiting for service at present. We keep that list and we move through it as much as we can but other respite services in our same area do not keep that relevant information because they are not required to, and also because there does not seem to be a space for it to go.

CHAIR: Do you say there is no consistent definition of "waiting list"?

Ms LLEWELLYN: That is correct. We look at some very large providers.

The Hon. TREVOR KHAN: It is more than that. There is not a consistent definition of "waiting list" but there is no consistency in the retention of the information?

Ms LLEWELLYN: That is correct, because there can be a culture in some providers around unmet need or waiting lists being seen to be a negative about their program so they want to be seen to be full because their output funded is based on being full and providing that number of hours continuously, but keeping a list that does not actually generate any further conversation or any change in the funding levels for them or for other providers, or that does not actually change the priority of people, because within waiting lists providers may not even keep a priority above that. So you can be number 20 on the list for respite, but that could be a matter of timing rather than whether your need is greater than the person at number one. So we do not have a level of sophistication in the system around what to do with waiting lists or the data that we collect because we cannot agree on whether to collect it, and then when we do, how to leverage that or use that to better service the clients.

The Hon. TREVOR KHAN: Is there any other simple data collection tool, apart from waiting lists—assuming you agree with the assumption I am making—that would be appropriate for the department to obtain/retain for the purposes of identifying what the needs are? Are waiting lists the appropriate measure?

Ms LLEWELLYN: I guess I would say that it is a measure and I think it is a useful one. For me though it is still a wait-list towards a particular model of service. So it is a wait-list for domestic assistance, let us say, so that is what people think they need because that is the service that is available. So they go on a wait-list for domestic assistance. We do not have a good way of finding out. Domestic assistance may not be the need; they have just been referred there because they have come out of hospital or they have come to a crisis. They sit on that wait list for a very long period of time. By the time they receive a service their needs may have changed again. They go back to another service, to another waiting list. They may not even get the service they were originally on the wait list for. There is something about understanding the need of the individual before they sat on any wait list and then understand what the model of service is that would best meet that person's need. At the moment the models are quite prescriptive, the outputs that go with them are quite prescriptive, but it seems to me that we do not always meet the need of a large number of individuals because they just move between waiting lists without their needs and their real aspirations and goals being met. Does that make sense?

The Hon. TREVOR KHAN: It does.

Ms SQUIRES: May I add a comment to that? In terms of what Sharryn is saying—I think my experience is much more with older people—say an older person is coming out of hospital and they have been referred to a domestic assistance waiting list and there they sit. In fact, if they had been able to get some rehabilitation restorative help fairly quickly to be able to help get them back on their feet and help them to get back into being able to cope with their own housework and put in place perhaps something like help with shopping, they may be then okay for another number of years. But, as Sharryn is saying, when help is not targeted and it is not timely that is when we start seeing needs becoming more complex, particularly for older people, than they need have been otherwise.

CHAIR: But who is in a position to determine how you deal with the waiting list, where you stand on a waiting list? What is targeted? What is timely? Is there any conduit? Are there any thoughts on a recommendation to us about how you deal with that particular issue of targeting? Each individual NGO has a specialist function and I understand you to be saying that you do not have the resources or the capacity to properly target the time.

Ms LLEWELLYN: I am not sure I am precisely saying that in terms of that we do not have that. We do not have a mechanism for where it will go. We do not have a clear understanding between providers that are funded and the department about what happens to information. We do not have through the funding mechanism or the agreement a way of saying "Every year we will provide you with a wait list or provide you with a snapshot of unmet need". That happens in Commonwealth programs, the Department of Health and Ageing, for example, and FaHCSIA; they ask for a six-monthly overview of unmet need and of areas of improvement and change. So there are other programs that we could draw on to look at how that would work well and how that then feeds into planning for government departments and into looking forward in terms of models of service.

The Hon. TREVOR KHAN: I suppose that is where I was going, because I could tell you are going to differentiate between the Commonwealth and the State. Is the information sought from the Commonwealth of a nature and style that could easily be replicated for a State program so we are not reinventing the wheel and therefore uses the model for determining need? I am concerned that an organisation could end up having to provide multiple different sorts of information.

Ms LLEWELLYN: That is right, and that is what we do now. Because my portfolio covers those two worlds, so to speak, I do see the benefit of providing that additional information, from a more qualitative point of view, to the Commonwealth departments that fund us and I do see over the time that I have managed those programs over the last seven years changes that get made and conversations that happen and negotiations around the types of services that are provided because of that information being fed in. It is one thing to feed it in and then there to be a black hole where nothing happens—so, information for information's sake—but where you can see a direct change, whether that is a local, individual service provider being contacted by a government officer to say, "I can see in your report that you have identified that you would like to do more outreach with indigenous communities. What is that going to look like?", it is that relationship that happens then with that government officer around how the service is provided and how that can be made more real and more responsive to what that community needs.

But getting back to the question around is there more meaningful information, I think part of it is about waiting lists, no doubt, and if we had an agreed idea of what that looked like and the purpose of that it would be helpful. We would also need to think about looking at measuring what the outcomes are of people receiving services already and whether those services are effective, whether they provide a good quality of service for individuals, whether they meet a broader need in the community about people being able to participate and being included in their communities. We do not have a clear picture of that at the moment in the HACC programs, for example, because, again, there is no mechanism to measure or to look at the data beyond the raw numbers of outputs that people are funded for.

The Hon. GREG DONNELLY: A number of submissions, including your own—and to some degree it touches on this but I would like you to elaborate on it please—are critical of the Government's current approach to managing the disability respite system specifically. As you understand and experience the current problems could you outline your thoughts about how they could be addressed?

Ms LLEWELLYN: I think that the easiest point to make is that there is not enough to go around. We seem to be holding the tension between families and between individuals and between other service providers about who gets a slice of the pie and the pie is not big enough. As I talked about before, we have a wait list for our respite program at the moment of 120 families in St George and Sutherland. Some of those families will be on that wait list for many, many years. Many of them have already been on the wait list for many, many years and there is no movement forward.

The Hon. GREG DONNELLY: With respect to those people who wait and continue to wait, how are they getting by? How are they managing?

Ms LLEWELLYN: Under great stress in many cases, at a loss to their family. We see constantly family breakdowns as a result of that. I am not saying that respite is the only area but in terms of having a family member with a disability or a chronic illness or any kind of need that needs to be addressed, we constantly see parents separating and divorcing; we see the siblings, particularly younger children, of those families often been left out, being in situations at school where they are not coping, not having friends that they can bring home and so on. There are many levels of stress. We see very high levels of unwellness—physical health and mental health issues—amongst carers, and the AAHW study that was done not so long ago pointed to the very high levels of unwellness, physical and mental unwellness, that carers encounter day in and day out.

Because in the Benevolent Society we operate the carer respite centre, the Commonwealth component alongside these HACC funded programs, we see a lot of the families on the wait list moving back and forth through the crisis respite that we offer at the Commonwealth level, which is, I guess, a bandaid in terms of meeting the really genuine emergencies that families have. But they have frustration with us because they feel that we are not giving them the ongoing support that they need and they are sitting on those lists for, as I say, many years—a family that has been on there for at least eight years continually needs the support and often, again, they move between other programs to get one-off type emergency care.

The other challenge is that families find they need to present themselves as being in crisis and not coping to get services, which is quite degrading for them as individuals and as a family unit to be always having to say, "We are not doing as well as we want to and we need that extra support". They are not exercising any real choice, I suppose, and they are not, I believe, having a right to the dignity they should have as carers and the amazing work that they do.

The Hon. GREG DONNELLY: In terms of the number of NGOs in the State providing disability services, we understand it is around 460 or thereabouts, could I get your thoughts about that number itself and the pros and cons of having such a number, and could I get your thoughts, looking into the future, about issues associated with so many NGOs operating in this important area?

Ms LLEWELLYN: I have been in many conversations about both ends of this debate and everything in between about having a smaller number of larger providers who perhaps give economies of scale or who are able to offer a broader demographic coverage or are able to provide the kind of data at a more sophisticated level than perhaps smaller providers can. But at the local level when we are looking at the diversity of the population that we are trying to support—we are talking about our core clients, our indigenous clients, our people with mental health issues, our people with very profound disabilities, our people with learning disabilities and so on and so on—we are talking about organisations that have started from a few parents getting together, feeling very passionate and feeling like they needed something just to support a particular level of disability or a particular type of disability that had not been acknowledged previously—for example, ADD is a particular one, or learning difficulties; there is a real groundswell that has happened around that—and those organisations and those needs perhaps would not have been met if it was not for those very small grassroots folk coming together and saying, "We need to do something".

I suppose, on balance, I always lean towards the diversity being the key rather than a number. I am not sure what the magic number is. But I believe that the grassroots community groups that come up through the needs of their families are what give us the richness that we need in the sector to really genuinely respond, and I think we would miss being able to support a large range of people if that diversity was not there.

In terms of coordination and communication I think we can always do better. There is no question that we struggle locally let alone regionally let alone statewide to talk about what is happening in our areas, what is the real need, what could we do better and so on. I think that is a constant challenge. There are particular positions locally called HACC development officers. There are also development positions within local councils that do an amazing amount of work to glue us together. Sometimes the glue gets a bit stretched but they do fantastic work around forums and interagencies and seminars and training and all those kinds of elements of sector development that I think are really important. So, I am leaning towards the middle.

The Hon. GREG DONNELLY: I think I understand the arguments behind what you have said. In terms of dealing with individuals with a disability, we understand from evidence from previous witnesses that we are progressively moving towards an individualised tailored model as opposed to, to coin a phrase, a bit of a cookie-cutter approach to providing services. What are your thoughts about that model and the ways in which that model, in your view, is the right way to proceed and how we enhance and develop that further and expand that further as a way of assisting people with a disability?

Ms LLEWELLYN: If I am hearing you correctly you are talking around models such as consumer-directed care and individualised funding and so on?

The Hon. GREG DONNELLY: Yes. What are your thoughts on that?

The Hon. TREVOR KHAN: Are those two things the same, individualised funding and—

Ms LLEWELLYN: Not necessarily. To me there is still a bit of a continuum about the level of control and choice that individuals have around the funding. We have sorts of hybrids of that, I suppose, in some programs and we have movement in some areas around giving up more control from the service provider and giving that towards the client. But it is a bit underdeveloped in most areas of the programs I would say.

The Hon. GREG DONNELLY: It is early days.

Ms LLEWELLYN: It is early days. I can highlight a couple of examples that we had in our submission around attendant care being in a program that operates very well from the point of view of an individual consumer exercising control over their care, exercising control over who provides the care and how, and being very active in that relationship. Because the precondition of that funding occurring is that that person is able to exercise that choice and control, to me that is a very positive model. We have a number of clients that we work with for other areas of their need. They might have an exchange with us around some respite from time to time, but they find that model to be extremely satisfying and very strengthening of them as individuals.

The Hon. GREG DONNELLY: That is the feedback they have provided to you, is it?

Ms LLEWELLYN: Absolutely. We also have an example of something moving more up the spectrum, away from consumer-directed care but still on the spectrum I suppose of individualised funding, with the ADHC-funded aging parent carer packages that have been implemented in the last two years. Originally those packages came out of the—and I always get to this wrong—the Commonwealth State Territory Disability Agreement [CSTDA]—

Dr JOHN KAYE: That is correct.

Ms LLEWELLYN: Thank you, I got it right. Looking particularly at ageing carer parents over 65, which we heard before the other lady talking a bit about, what that means for an older person with a child or an adult with a disability and then planning ahead to look at what they need in terms of their care needs but also the person they are looking after. So there is Commonwealth funding moved through to New South Wales in the last two years, and the Benevolent Society does operate a group of those packages in southern Sydney. Where we have been able to operationalise those with individuals—and again it is about giving them the say in what they would like to do with those packages, with the amount of money that they are allocated being about $7,500 per year—they may choose to use that for respite and some personal care and some social support and some transport and/or, and/or. Still within the traditional models of care however—I just pop that in—not necessarily things that are outside, which I guess is why I would sit it at the other end of the spectrum at this stage in terms of real choice.

But there is hope there in that process about handing over the conversation, handing over the choice, giving the consumers that information about what is available for them. I suppose particularly for ageing carers that is absolutely essential because many of them come into the system very late in their lives when they have had a series of misadventures and very good reasons not to trust the system, by the time they encounter our program, for example, they are not really wanting us to be telling them what to do, nor should we. That particular package program is quite exciting because it does give them a more genuine sense of involvement and inclusion, and they come up with resource ideas that are much more creative than probably we would.

CHAIR: On the question of not telling them what to do but assisting them on how to do it together with the issues you earlier referred to about heading towards consumer choice and the difficulties you have with geography, regions, the size of organisations, that in-between step where you have got those HACC development officers with the ability to support management and administration that enable or empower the consumer to have real choice informed by the community at large, and to have skilled workers and workers who understand the industry, can you give the Committee any advice, firstly, as to how in an organisation such as yours, and in much smaller organisations, you ensure your staff and volunteers are properly trained? Secondly, do you anticipate expanding your workforce in the future?

Ms LLEWELLYN: I think our organisation is in quite a privileged position because we do have resources that would call on in terms of research internally and we also have a very strong commitment towards learning and development for our staff, whether that is paid or unpaid. We really are quite clear that everyone in our organisation has access to training and that we have qualification levels that we expect to see and if we do not have those qualification levels we support people to obtain those. So for an organisation of our size with that culture and commitment around that work it works well for us. Where we have smaller organisations locally who need that extra support ADHC does fund through the HACC program some very positive training programs for volunteers and for paid staff—those are offered at no cost actually for HACC-funded services. They are extremely effective because they are unable to bring in experts around particular training areas that people identify with in the region.

CHAIR: Are you satisfied that everything is covered and there is no need for the Committee to make any recommendations in that area?

Ms LLEWELLYN: I think I would still go back to my point around indigenous providers and organisations. I am not suggesting that I am speaking on their behalf in that sense, but my observation would be that there is a need for them to receive some support around the training of their staff and, I guess, building the capacity of Aboriginal people within communities to support their folk rather than it being outsourced back to the mainstream services where that may not be culturally appropriate.

CHAIR: Would it be appropriate to outsource to some sort of government-brokerage system or a system through yourselves to enable the management and administrative side to be dealt with so they can deliver a service at the choice of the consumer without all those add-on problems of administration, management, training, acquiring of skills et cetera?

Ms LLEWELLYN: I would not suggest we would be outsourcing but I think what we could do better is to work in partnership with those organisations and look at how we could share the knowledge and also they could share their knowledge with us about what they have learnt. They are often very strong, grounded organisations that really do have consumer-directed care. We are sitting here talking about moving towards that but many of the indigenous organisations that we work with know what that looks like because they live and breathe within their communities. They talk to their people all the time. They understand intergenerational needs. They understand what it looks like to have someone really struggling, and how they can all work together in kinship for that to occur. I think there is lots of learning that could come our way as an organisation in terms of that.

CHAIR: Sure, on the delivery side. But in terms of the management, administration and dealing with the bureaucracies et cetera that may not be strength. Is there an ability to diversify and divide up those management issues as opposed to service delivery issues?

Ms LEE: That is if it is funded. If we are provided with that funding we could incorporate that. I think it is a very good question in terms of how we model the way we are going to deliver those services in a consumer- directed fashion and provide choice. We need to, as Sharon mentioned, provide enormous amounts of information and support particularly to the aged care and community care sector, but we also need to be able to provide administrative and budget support that is linked in very closely to us as an organisation. Also with your second question about workforce, in general terms we are in big strife with a skilled workforce and maintaining that skilled workforce with an ageing population that has complex care need delivery out there, and that is increasing as our baby boomers are moving forward. That is a big issue for providers.

The Benevolent Society—who we are representing here today—is very innovative. My position is one of looking at the current research out there and trying to implement that into our daily practice and care delivery. I spent the last week developing models about how we can make our consumer-directed care delivery model that puts us in the forefront of doing a good job for our consumers and being able to measure that in effectiveness and evaluation as well. I have not seen this type of position in any other provider at all. So I think we are really out there trying to encourage that in practice on the coalface.

CHAIR: I am interested to know if there are any individualised models out there similar to the relationship between, for example, myself and my staff. I have complete choice but I do not employ them and I do not train them—I do not have those responsibilities. Are there any models out there along those lines?

Ms LEE: No, the models are very academic at the moment.

Ms LLEWELLYN: Internationally there are models in the United Kingdom, for example. The Commonwealth in particular are keen on promoting the consumer-directed -care type approach. They have just funded in aged care respite packages and also community-aged-care package type care based on consumer-directed models, but this is all at the very pilot, beginning stages. Just getting back to your question again around indigenous organisations, in funding rounds when programs are set up there are opportunities for organisations to form consortiums around a particular funding project. So a level of funding may be made available and the department does encourage where that is possible for organisations to come together and make those agreements.

That is an area where there could be some more support given to the organisations that wish to do that, some more expertise around what that actually means. It is words on paper that says: We would like to develop an agreement around how we work together, but often when you get to the next stage of the funding arriving and what that will mean in terms of governance, decision-making, policy, and in terms of who is holding the can, I suppose in some circumstances, who sets the standards, all those things, I do not think we have that level of sophistication. That would be an area where we could be supported more.

Ms SQUIRES: May I? If I could just make one comment on what Sharon has just alluded to. Where the rubber hits the road around organisations working together, our organisation has a lot more of that experience in the children's area. That is one of the things why we find we enjoy working for our organisation so much—there is so much learning we can have rather than just being a single focus; we have that wider group. In the children's area there has been a lot of experimenting with models where one organisation may hold the budget and distribute it to others. What we have found is that we have actually in that area developed expertise around how you have those negotiations and how you write the agreements—it is actually incredibly complex. As we move particularly with older people into that area of the consumer-directed we are able to draw on that learning from the children's area. That would be something I would put to you: The need to look more widely than just a disability focus or just an ageing focus to good practice.

The Hon. TREVOR KHAN: Two things. First, could you provide me—because I cannot speak for the Committee—with some sort of outline of that model you have just described? Second, in dealing with the children and what I assume is the Department of Community Services, can you tell us anything about the data collection methods of that department that perhaps would be of assistance to ADHC? You shake your head, which is not a good sign.

Ms SQUIRES: The organisation may well be able to, and certainly on notice. I think the three of us personally could not but certainly taking that on notice we could certainly bring back some information and provide that to the Committee.

CHAIR: On notice to the committee, not to Mr Khan.

The Hon. HELEN WESTWOOD: You touched on workforce capacity a little earlier. I would like to broaden that beyond indigenous-specific services or staff to dealing with your general workforce dealing with ageing and disability services. One clarification, do you have residential care services other than respite? I am not sure whether your respite is day respite or whether it is residential? In terms of workforce capacity, are your turnover levels in staff recruitment, training and maintaining that staff of concern to the organisation or even perhaps out of step with staff in your other areas of service delivery?

Ms LLEWELLYN: We only operate residential care in ageing at present. Our work with people with disability, carers and older people is primarily in the community in their own homes.

Ms SQUIRES: May I? I would like to also clarify that the Benevolent Society has in the past few years taken a position that in fact we will no longer be providing residential care for older people in residential aged care facilities in a traditional way, because our main focus is about delivering innovative services and there is not much opportunity for innovation in residential areas. We gradually have moved away from that. The whole purpose of our doing that is to focus on the community care and support of primarily older people but increasingly people with disabilities. We are very interested in new residential models, such as the apartments for life model that I know Dr Kaye is familiar with in our work. We are looking towards a more innovative approach. With regard to turnover in our organisation in general, we are not particularly concerned. We think we do an excellent job of recruitment, support and training. We believe we do that well.

Ms LLEWELLYN: In terms of turnover we are looking mostly at coordination level and case management level staff. Our most recent staff survey told us that we have reduced our turnover from around 25 per cent to about 14 per cent over a two-year period, which we are quite pleased with. We have volunteers in our direct service delivery and again we support them quite closely. We have a couple of positions within our head office, so to speak, that support volunteer recruitment and at the local level we work closely not only with the volunteers themselves but also with the Home and Community Care volunteer programs in our region. We provide that training, guidance and mentoring as well. All our case management coordination staff who are in the office and out doing home visits, assessments and reviews and so on, have a tertiary qualification, usually in a welfare/social work-type background. As I said before, we have a very strong culture of maintaining learning and development as well.

With our direct service provision and the workers on the ground working with the families we utilise a brokerage model for the majority of our services. We have contractual arrangements with mostly for-profit providers, but also some non-profit providers. We engage them and work extremely closely with them in working in the families. Those relationships are pivotal to us working well and central to the families' satisfaction. We look at having in our contracts requirements around the kinds of work that they will do and also around qualifications and the training and support they offer their staff.

The Hon. HELEN WESTWOOD: With regard to waiting lists for services, how do you prioritise the clients who are going to receive those services? Is it about complexity of disability or level of disability? You referred earlier to people with ADD as an area that is growing, so I will use it as an example. Is someone whose disability is ADD and is in need of respite likely to receive a service as quickly as someone who has physical and intellectual disability?

Ms LLEWELLYN: That is a really good question so I will take my time thinking it through. We certainly look at complexity. When we look at the 120 people on our wait list for respite at the moment we do not just go to the next on the list. We look at the complexity and the nature of the caring relationship and the family structure and how things are going there. We look at the status of the siblings involved as well to get a general health measure of what is happening to that family and to the carer in a particular situation. We need to look at other services that may already be in place for that family, whether formal or informal services, and even though they may not be adequate that provides a measure against another family that may have no services at all. When I talk about the respite program, for example, we are only looking at the level of funding we receive. Families receive about four hours a week respite, which is by no stretch a large amount, so when we are making these decisions and looking at families that may be receiving four hours somewhere else as against someone who is receiving nothing we are talking about decisions that are made with a great deal of trepidation and concern.

They are hard decisions and we need to balance those resources between families and within the organisation and between organisations. We certainly look at the carer relationship and we certainly look at the complexity. We look at whether there may be no other providers that are willing to provide services to the family. In particular that means we have higher unit costs for a lot of our respite clients because we tend to take on clients with complex medical needs, very severe needs in many cases. Whereas in other programs they would only be offered a group setting we will do one-on-one respite with that individual. We will take on clients with behavioural issues where there is a behaviour plan we can put in place. We tend to stretch ourselves, I am proud to say, towards those areas. However, on the ground that is a higher cost service that we are offering, so we prioritise in those kinds of areas as well.

CHAIR: Thank you for appearing before the Committee today. I am sure there will be some questions on notice to be sent to you in the next couple of days.

(The witnesses withdrew)

(Luncheon adjournment)

GREGORY KILLEEN, Senior Policy Officer, Spinal Cord Injuries Australia, 1 Jennifer Street, Little Bay, NSW 2076, and

SEAN JOHN LOMAS, Policy and Advocacy Manager, Spinal Cord Injuries Australia, 1 Jennifer Street, Little Bay, NSW 2076, sworn and examined:

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

Mr KILLEEN: I am appearing as the Senior Policy and Advocacy Officer of Spinal Cord Injuries Australia based in Sydney. If need be I can answer questions from a ADHC consumer perspective.

Mr LOMAS: I am appearing as the Policy and Advocacy Manager at Spinal Cord Injuries Australia, a Sydney-based advocacy organisation that also reaches out across Australia.

CHAIR: Would you like to make an opening statement before we ask some questions?

Mr LOMAS: I have prepared a very brief opening statement. Spinal Cord Injuries Australia, formerly known as the Australian Quadriplegic Association, was established in 1967 by a group of young men who acquired and survived a spinal cord injury resulting in quadriplegia. They survived due to advances in medical science. There were no government-funded disability support services and programs to enable them to have the opportunity to live in the community and to be productive members of society.

Spinal Cord Injuries Australia continues to represent and support people with spinal cord injury or similar conditions. It employs many people with a disability and provides a number of services, including information and referral, advocacy, peer support, out-of-hours emergency nursing services, accommodation and employment services. Spinal Cord Injuries Australia is aware of the ongoing benefits to people with a disability, their family, friends and carers due to the provision of disability support services and programs, particularly those which have effective and efficient management and which are appropriately funded to meet their needs.

In providing submissions to this inquiry, both written and verbal, we will draw on member testimonials to demonstrate the issues communicated to us. Our role as an organisation is to provide that information in the same candid fashion as it has been relayed to us. Although many of the comments received by our organisation on the effectiveness of ADHC and even the Stronger Together package of funding have been negative, we acknowledge the difficulties that ADHC must face in providing a diverse portfolio of services effectively in New South Wales to many thousands of people—more than 52,000. I thank the Committee for inviting us to give evidence today.

CHAIR: Your submission states that there seems to be a growing gulf between the application of policy in metropolitan Sydney and regional New South Wales. Can you explain your statement and, if possible, use examples to illustrate the point?

Mr LOMAS: This often relates to home care provision in the regions. I receive perhaps one or two calls a month on this basis from people living in regional New South Wales saying they have been informed by their home care manager that an element of their service will be changing. My response is usually that I have not heard anything about it. I contact the ADHC head office in Sydney and I am told that they have it wrong. I am then piggy in the middle and have to inform ADHC regional staff that that is not the case. I certainly should not be playing that role as an advocacy worker; it is not my role to educate regional ADHC staff or to ensure that they are complying with policies created through consultation in Sydney.

The Hon. HELEN WESTWOOD: Mr Lomas, why do you think regional staff are uninformed, misinformed or lacking in understanding of the role of ADHC and the current policies? I am not saying you do know, but do you have a feel for that?

Mr LOMAS: It is difficult to say. Generally across many other services, not necessarily only the disabilities field, there is a separation between metro thinking and development of policy and regional and rural thinking about policies. Perhaps this is just a victim of that. I do not know how ADHC consults with its regional workers to ensure that they are informed and that they receive circulars. Research we did for an inquiry into aids and equipment indicated that a great deal of training was provided to frontline staff by the managers. However, managers generally rolled over every two years and there was not necessarily reinforcement of training or reemphasis of the guidelines and the policies to the new managers. They were passing on information through word of mouth. It was like Chinese whispers and over an extended period things can get skewed.

There is also potential with regard to interpretation of policies to suit the operating environment. A policy might work fine in Sydney but not in Mudgee because they have a number of other constraints, including distance, availability of carers, occupational health and safety compliance and so on. They may skew the policy, but we do not know whether the fact that it is not working is fed back to Sydney head office or whether any consideration is given to modifying it to ensure that it does.

The Hon. HELEN WESTWOOD: Mr Killeen, do you want to add anything?

Mr KILLEEN: Recruiting staff is sometimes harder in smaller rural and regional areas. In Sydney there may be many service providers providing choice and options such as normal government services apart from home care services. There might be a monopoly in one area and consumers may not have an opportunity to complain or may feel constrained in complaining. If they complain about the one and only service available, where do they turn? The services may not be quite as good as they could be.

The Hon. HELEN WESTWOOD: What about the quality of the service? Do you find there are differences between the regions and Sydney and even between the types of services that your client group consumes? I include attitude, cultural awareness and understanding of disabilities. Is that an issue? If so, what complaint mechanisms exist? Is there a complaint mechanism that you believe satisfactorily resolves those issues?

Mr KILLEEN: We have had feedback from members about this inquiry through our website. Some people in the regional areas have made some fairly strong comments about the services they are receiving. Some person wanted to have a shower in the evening rather than in the morning. He said, "Do you ever change your shower routine from morning to late shift? I did once and received a visit from the boss and was verbally chastised. Glad to get rid of them."

Dr JOHN KAYE: Who was that?

Mr KILLEEN: A consumer on the mid North Coast.

CHAIR: Who was he describing as the boss?

Mr KILLEEN: I assume it was the manager.

Dr JOHN KAYE: The local ADHC manager?

Mr KILLEEN: Yes. He chastised him for wanting to change his shower time from morning until the evening. He states:

> I went from a respected contributing member of society to a second class citizen who is not taken seriously by DADHC at any level and, frankly, I just can't take it anymore. I had a raft of complaints ranging from simple breaches of code of conduct, "bullying" by the branch manager, breaches of confidentiality et cetera, service withdrawal or threats et cetera, to abuse of power, falsifying public records, breaches of the Public Finance and Audit Act regarding the outsourcing of services and agencies et cetera.

This is someone who has been the recipient of that service for over 25 years. There is another one, which states:

> For over 25 years I have been a client of Home Care and find that the service has declined to an alarming state resulting in poor health management, bad hygiene, security risks.

CHAIR: Is that metropolitan or regional?

Mr KILLEEN: I believe that is regional as well. We have taken out the names of the people, their identity, but we have their details. They have given us permission to quote from their statements to us.

Mr LOMAS: We put all our policy work on our website. Generally we get very little feedback, other than if we go out and force the questions. For some reason, this has really sparked off and we have been getting an awful lot of stuff coming in, particularly from the regions, where people have thought that this was a chance for them to be able to communicate the issues that they face. In many agencies in New South Wales that I have come across in my work with Spinal Cord Injuries Australia, there does seem to be a little bit more of an empirical, empire-building basis once you are outside Sydney itself. They have their clients, it is their office and their staff and they run things fairly much as they wish.

I would have thought that it is written down anywhere that ADHC has the right to chastise staff for changing service times, we certainly know as well of cases where in the evening a gentleman wanted to go to bed at 9.30 or 10.30, and had been doing so for a long time. He wanted to stay up and watch a late program and then go to bed. That was an agreement with his Home Care service. That has gradually been cut back and he now goes to bed at about 8.30, because they are trying to shove him in and get him done so that that person can drive on to somewhere else and see another couple of people, or go down to the pub. It is not really quite right that that is happening. I do not know to what degree that is happening in Sydney; we certainly hear about the most awful examples in regional New South Wales, but I am sure it is not the same. I am sure there is a different degree of service in Sydney than in regional New South Wales.

Mr KILLEEN: I would like to comment from a consumer's perspective, I will put my consumer hat on. I live in Sydney and I do not experience any of the things that are coming out of the regional feedback. I have been using Home Care, for personal care, for some 22 years now. Some workers have been with me for 18 years and I do not experience any of that at all. I would not survive in the community without Home Care's personal care support service and other programs in Sydney that run this essential service. I find that the people who come to me are fairly well trained and do their job. I am not saying that everything is perfect. I am not saying that there is not an initial hiccup in the service, where sometimes someone does not turn up. The coordination might not have rostered someone on, or something like that. But overall, I find it reasonably good. That is my perspective. It provides services to lots of people.

CHAIR: You have a great degree of choice? If someone comes to you for personal care who you find you cannot have an interpersonal rapport with, you tell Home Care and they change the person?

Mr KILLEEN: Yes. I have had to put up with things over the years, you know. But I do not have too many issues with people or clashes with people on a personal basis. In all that time I have never asked for someone to stop coming.

CHAIR: You do not feel you do not have choice?

Mr KILLEEN: No. I do have choice, because sometimes people are not available and it is difficult to get someone to come. Of the people who come, about seven different people provide support. So, when someone is off or on holidays or whatever, or calls in sick, that narrows it down to maybe shifting the time I have my service rather than get someone I do not really know. That is a compromise.

CHAIR: Can you imagine that the Home Care branch manager in a remote or regional area would have difficulty finding staff and there may be occasions when, with not the best of interpersonal skills, they may have said that they cannot find anyone else?

Mr KILLEEN: Absolutely.

Mr LOMAS: Whether that is communicated back to the client is a question. You certainly have two testimonials from people saying that they spend the nights sitting in their chairs because no-one contacted them. They do not know when someone is coming. They have no idea what has happened. They will sit there for the evening, generally in quite a foul state, risking skin breakdown and a whole host of issues.

CHAIR: That may be not because of choice, but just the way things panned out on that occasion. That is a problem.

Mr LOMAS: It is why we put forth in our submission the option for an out-of-hours back-up number for ADHC staff, and also for the ADHC clients. That is a simple way for a properly created scheme to provide some degree of certainty, that should a carer not turn up, for whatever reason—they have every right to be ill, to have the odd dodgy oyster—and call in outside regular hours to say that they would not be in tomorrow because they do not feel very well, then you have some degree of support for that individual.

CHAIR: Is that not happening?

Mr LOMAS: No, it is not, not in any shape or form.

Mr KILLEEN: Not from ADHC-provided services. It is a requirement for ADHC-funded services. That is a bit of do what we say, not what we do!

CHAIR: That is one of your recommendations to us?

Mr LOMAS: It is one of our strongest recommendations. It is something that we have been talking about for over 12 months, and we still have not any traction on it. It is a very important thing, it is a simple and logical thing to do.

Mr KILLEEN: It is a simple process now that the ADHC rostering and time sheets are all done web-based. The coordinators can access those rosters and time sheets through the Internet, which means that outside of the regular Monday to Friday 8.30 a.m. to 4.30 p.m. administration hours, if there was a phone number for that branch diverted to a mobile phone that was carried by a coordinator with a laptop who could be on a rotating roster to be on call where they can look into the database and find out if someone has called in sick. They could look at who their clients are and at what workers would go to that client. They could give the authority to call on those field staff to see if they could get across and provide that service. That would be an ideal situation. The technology is there now to do that.

The Hon. MARIE FICARRA: I notice that in your submission reference is made to the Randwick-Botany Bay Home Care Branch which has instigated something like that.

Mr KILLEEN: That is right. They have a care worker, not a coordinator, who is out there working, who carries a mobile phone. Clients with high needs and the field staff, if they are unable to turn up to work the next morning or that night, can ring that mobile number. That person carries not a laptop but a couple of sheets of paper; one with clients' numbers, and one with field staff numbers, and tries to coordinate, as best she can, a back-up service. The Randwick-Botany area has one of the highest per capita areas of people with high support needs, as the spinal injury unit was based at Prince Henry hospital. The Australian Quadriplegic Association was there and there is a lot of public housing in the area as well with lots of people with disability living in the area.

The Hon. MARIE FICARRA: That is one branch that has gone forward with the initiative, others have not followed. There is still more that could be done, but it is heading in the right direction?

Mr KILLEEN: Yes, and that service has been around for a few years. It operates outside normal operating hours.

CHAIR: I understand you to be saying that the Randwick-Botany branch has a large proportion of spinal care people?

Mr KILLEEN: And those with other disabilities, yes.

CHAIR: And personal care needs. Out of the 170-odd branches, not too many would be in regional areas. The difficulty that you are confronted with is that the majority of branches say they cannot afford the cost of an on-call allowance, 12 hours a day, seven days a week?

Mr KILLEEN: For a coordinator to coordinate that service.

Mr LOMAS: That has not been discussed. You can bring areas together and just have one person to serve a very large area, and they just have to have the numbers and the details and they can coordinate from there. You do not have to have one in Mudgee, one in Dubbo one in Wellington.

CHAIR: It could be done regionally?

Mr LOMAS: Absolutely.

The Hon. HELEN WESTWOOD: Is Home Care, ADHC, the provider of services that your clients are most likely to receive services from? Do they have monopolies in some areas? Are they the only provider of the majority of services that your client group would need?

Mr KILLEEN: I would say that ADHC has a branch in every part of New South Wales, but there may be areas where there is no non-government service. So you would find that Home Care New South Wales would be the only service provider in the area.

Mr LOMAS: I cannot remember the ratio off the top of my head. Is it 60:40 government to non-government?

Mr KILLEEN: I am not sure but we could take that on notice and try to find out that information.

The Hon. HELEN WESTWOOD: Yes, and also the range of services that your client group needs. Are they mostly within ADHC and Home Care or are there services that other government departments or non-government organisations would provide?

Mr LOMAS: We will have to take that on notice.

The Hon. GREG DONNELLY: I apologise for my delay following the lunch break. You may have already covered this. I refer to one of our questions on notice. Your submission states that there seems to be a growing gulf between the application of policy in metropolitan Sydney versus regional New South Wales. Did you cover that while I was out of the room?

Mr LOMAS: Yes.

The Hon. GREG DONNELLY: I will move on to the next question. A number of submissions, including your own, have raised concerns with the provision of community transport services. That is specifically dealt with on page 4 of your submission. Could you briefly explain your experience of the problems you have encountered with the transport arrangements and suggest ways that ADHC could improve such services?

Mr KILLEEN: Some of the issues for some consumers are that all community transport services have vehicles, but not all the vehicles are wheelchair accessible. I believe there needs to be some sort of policy or requirement that if they have a vehicle the vehicle should be wheelchair accessible or another option is they broker it out if the town has a wheelchair accessible taxi in the area. If the service provider does not have a wheelchair accessible vehicle—which obviously costs extra money to have that accessible vehicle with a hoist and wheelchair restraints—they might be able to outsource and organise and pay for a cab to provide community transport for that person. Community transport is Home and Community Care [HACC] funded, which is for younger people with disability and the frail aged to support them to live in the community. People with high needs and other people with disabilities require a whole variety of services, of which community transport would possibly be one if they do not have their own vehicle. If there are no taxis in the area some people could be isolated and not be able to leave their home. A good recommendation would be that all community transport services should have at least one accessible vehicle and funding might need to be provided for that.

The Hon. GREG DONNELLY: I gather from your evidence that this is not an isolated issue.

Mr KILLEEN: No.

The Hon. GREG DONNELLY: Is it a general issue that has been reported to you?

Mr KILLEEN: Yes. It is also an issue when it comes to disability in rural areas. For kids who need to go to school and the school buses are not accessible, they need to have their own transport. In regional-rural areas often close-knit communities try to make do with what they have got and cross support services. There is a real need for community transport to address the issue and if they are going to be provided with funds to provide community transport, then at least one vehicle have some mode of accessibility so it can be provided.

The Hon. GREG DONNELLY: It is in the fleet?

Mr KILLEEN: It is in the fleet.

The Hon. GREG DONNELLY: On page 4 you note that people who acquire physical disability in some instances encounter delays when accessing services after being discharged from hospital and this can cause ongoing issues. For the purpose of the Committee, could you explain the implications that can arise and perhaps give an example to demonstrate how it plays out?

Mr KILLEEN: Do you mean when they are in hospital and want to be discharged?

The Hon. GREG DONNELLY: In relation to the delay, once they are discharged, in accessing services that they need. Presumably that has a compounding effect on the situation.

Mr KILLEEN: Yes, the transition from hospital to home and getting access to programs.

The Hon. GREG DONNELLY: The delay issue.

Mr KILLEEN: The home modification scheme where people own their own home and they need to have it modified, if there is a lack of funding to modify the home and people do not have their own means of funding to modify it there can be a requirement for them to be transitioned to another type of accessible accommodation before they can go home. We are aware of some people going home when the home is not modified and making do, getting carried up and down a few stairs to get in and out of the home. They want to be home, they want to be out of hospital and they are well enough to leave hospital but they have to make that sort of compromise, which is unfortunate. We also are aware that the home modification scheme level three, which is $20,000 and above of funding and does major renovations, ramps, doorways, kitchens and bathrooms, that had run out of money before Christmas last year for this current financial year's budget.

Mr LOMAS: On the topic of discharging someone to a house that needs to be modified but is not modified, there is serious risk for other services coming in with occupational health and safety and care support because everything is different. The physical work that they are going to have to do is going to be in a far worse state. They will not have access to ceilings because there will not be any load-bearing areas. They will have to manhandle people into inaccessible bathrooms. Carers are not able to do that work because of occupational health and safety regulations. It puts the client in a really bad situation. We have heard of instances and there is a lady I know in particular as an example who has been trying to be discharged. I believe she has just been discharged from the Prince of Wales Hospital into the community. She was waiting for over 12 months for her modifications.

Because she was waiting for over 12 months for modifications they had to move her from the spinal unit onto a maintenance budget, which then hides her statistically because she goes into the general pot within the hospital. She was ready to go. She was supposed to be discharged after about six months of being in. She has just been discharged recently. The reason why it took her a while to be discharged as well was through the sheer stress of having to wait to be discharged from the hospital she ended up having a nervous breakdown, which put her into a particularly bad place and they were unable to discharge her because they were afraid that she would be at risk to herself. It did not work out.

Dr JOHN KAYE: How long was she in hospital for?

Mr LOMAS: The total time was two years.

Dr JOHN KAYE: How long did she need to be in hospital?

Mr LOMAS: About six months.

Dr JOHN KAYE: She was in hospital 18 months longer than required?

Mr LOMAS: Yes. It is not just necessarily the home modifications. Because she had been there for a long time she starts to have other issues and that lengthens the time as well. She certainly was waiting for a very long time to have modifications undertaken.

Mr KILLEEN: When people are in hospital and cannot leave, obviously they have to be occupying a bed which is preventing other people from getting into the hospital system. It is a false economy not to spend the money to get people out. It is blocking the bed from someone getting in.

Mr LOMAS: If you can access the Lifetime Care and Support Scheme, that person would have been transitioned into temporary accommodation which would have been sourced through a case manager and the whole thing sorted out. They would have got by in that instance and they would have at least been out of the hospital setting.

Mr KILLEEN: It is not just home modifications, it could be waiting for approval for an attendant care program or in lieu of that the high needs pool, which is provided through Ageing, Disability and Home Care. It is issues like personal care and accommodation. It could be a means of support.

The Hon. HELEN WESTWOOD: You have raised the issue of poor mental health. Is it common for people with spinal cord injury to also have poor mental health following the injury? If that is the case, is that need adequately met? If it is the responsibility of ADHC, does ADHC need to provide appropriate services for the mental illness as well?

Mr KILLEEN: There has been the development of a resource for people with spinal cord injury to meet their psychosocial needs, which was launched at the Royal Ryde Rehabilitation Centre by Marie Bashir. That was at the end of last year. It is a resource kit that was put together to support people with spinal cord injury who might be diagnosed with some mental health issues following the spinal cord injury. Obviously people deal with their situation differently.

Mr LOMAS: We provided a detailed paper which we worked on with the Australian and New Zealand Spinal Cord Injury Society and a couple of professors within the field of mental health on the National Suicide Prevention Strategy. We found data to show that a person with an acute physical disability is four times more likely to contemplate suicide than a person who does not have that degree of disability. We noted within the National Suicide Prevention Strategy there is only one use of the word "disability" and that was in relation to the elderly and ageing, which certainly did not address many of the issues that people feel out there. We have done quite a lot of research into this. A person who receives a spinal cord injury does not necessarily have a mental health problem. It is often the system that grinds the person down. It is probably terrible to say this but with certain other disabilities where there is mental impairment it can be a blessing because you do not understand fully the things that are going to happen to you. With a spinal cord injury it does not necessarily follow that you have any degree of mental impairment. So you know everything and it is tough.

Dr JOHN KAYE: What about the situation of people who have comorbidities—a spinal cord injury and another type of disability that might result from the incident that caused the injury in the first place? Is it true that in such a situation comorbidities generally are not dealt with well?

Mr LOMAS: I would say it is true in all cases. There are organisations that deal with different aspects of these things. Generally within the advocacy sector and our sector you look at where a primary disability is recognised. If the primary disability is a spinal cord injury then that is what we work with and we liaise with other agencies to try to bring in the expertise that you need to deal with other aspects that may affect the individual. It is tough when you have to navigate those kinds of pathways when you are looking at a person who has an acquired brain injury and a spinal cord injury. It is difficult.

Dr JOHN KAYE: Has ADHC done things to smooth that pathway?

Mr LOMAS: I could not say yes and I could not say no. I would not be doing them credit if I said no and I do not have the information to be able to say yes.

Mr KILLEEN: ADHC are dealing with people once they get into the community. If people are having issues it would probably be picked up by the care workers or if they are living with family. Obviously we hope that someone would report back to the ADHC branch managers if they noticed that people were having an issue at home or their families would pick something up or it may be diagnosed in the beginning.

Dr JOHN KAYE: We spoke before about the differential between urban and rural and regional service provision. Part of it is structural and part of it is distance from Sydney. What about the situation of Aboriginal people with spinal cord injury? Do you have a sense of the quality of service available to Aboriginal people with spinal cord injury?

Mr LOMAS: It is difficult once you get onto the topic of Aboriginals with spinal cord injury. We have provided services to a gentleman in western New South Wales who was treated absolutely disgracefully by the

Department of Housing and by ADHC. It made the news and everything and it was quite a big story. Yes, I do not know. It is difficult to say whether it was particularly because he was an Aborigine, whether it was just because he was in a far-out area—he was on an estate over in Dubbo—or whether it was just because they were trying to clean house and he just got caught up in the middle of it but certainly he was not treated in a very decent, respectful manner.

Mr KILLEEN: DADHC has Aboriginal Home Care specifically targeted for people who are Aboriginal.

Dr JOHN KAYE: Has your organisation received any feedback on those services?

Mr KILLEEN: No.

The Hon. MARIE FICARRA: Your submission refers to ADHC's policy of fee for service. How has that panned out for users? Have their needs been met? Can people not access it or are reluctant to access it because of that fee?

Mr KILLEEN: There are a whole variety of ADHC services—personal care, respite, community transport, post-school options, transition to work—that people use. When people apply for those services they are always asked for information on their income and assets but no-one ever asks what are their outgoings. People with disabilities have got the extra unavoidable cost of having a disability that the rest of the community does not have. So they have always been asked to provide—I believe it might be an ADHC requirement that people be charged a fee for service. Some people who are often reluctant to pay a fee for service feel if they do not do that they will not get access to the service and they often need multiple services. The fee structure is open to the service provider. So, for instance, I am on a committee of a neighbourhood centre and it provides out-of-hours respite and that sets its own fees of what it charges for the service. So it is not a structure that is given to them by ADHC, it is the structure that is set up by the service provider so it could vary, so it is not uniform.

The same as with comparing personal care support provided by the high-needs pool, through NSW Home Care, people will pay a fee for service for that but if people get access to the attendant care program they pay absolutely nothing for that. And so they get up to 35 hours of direct personal care, they can also tap into Home Care and get domestic assistance where they might pay a fee for service for that but you might get two equivalent services, because some people who are on the attendant care program have actually chosen NSW Home Care to be their service provider, so they will not pay a fee for service for them because their money is allocated from their attendant care package, where someone getting the same care worker coming along providing the same service because they have a similar disability, will pay a fee for service. So it is not quite equitable. I am not suggesting people on the attendant care program pay a fee; I am suggesting people who are on the high-needs pool do not pay a fee.

The Hon. MARIE FICARRA: As a donor to the Italian care program I know that is right. It is a gross inequity. You touched on the home modification program. How can we rectify the home modification program not by just putting in more resources but the timing, assessments, transition from hospital to home and all those things?

Mr KILLEEN: I think the quality of the actual modifications being done by certain companies do that. We are aware of a number of companies that have done some very poor modifications to the homes of some people as a result of which the people in regional areas cannot even get into the rooms or down the hallways. I do not want to name the company but as reported through our regional offices they have been having all sorts of problems with people who undertake certain work which is all paid for by the home modifications scheme.

The Hon. MARIE FICARRA: There are not good enough guidelines, or quality checks or supervision of work?

Mr LOMAS: I think it is a question of early intervention—you know getting in there early with discussions around what modifications need to be done and then starting to plan for those because they do not happen overnight. As Greg just said as well, you have to look at quality control. If you plan far back enough for these things to happen in the future then you will end up with a fairly decent modification. It could well be that you allot funds at the early stage and then you are being sure that they are assigned to that individual as you then go through the assessment process, and instead of what modifications could be done, then you can just fund that directly off from that pot as opposed to presently when the application goes in, the person is left in limbo, then you can wait a long period through the local home modifications provider who may well be very good at their jobs, and many of them we have heard of do an absolutely sterling job managing with very scant resources to get some degree of modification done to properties. That could be a way to address it. But certainly let us just roll it back and try to get these services attached onto the individual as early as possible, as opposed to waiting until we get to the last possible minute and then getting them moving on.

The Hon. MARIE FICARRA: When you get the modifications, depending on the provider and the region, they are impractical or of good quality?

Mr LOMAS: If it is not quality, you have an issue there in that, as I mentioned before about complying with occupational health and safety for care staff. If you have got a ceiling hoist that does not work then you have to get yourself a portable ceiling hoist. Where do you get a portable ceiling hoist from? They will not touch you unless you have it or they will double care you. If they double care you, they bring in two carers to support you through lifting. Will that then come off your total number of weekly care hour allotment?

The Hon. MARIE FICARRA: Better co-ordination and earlier intervention?

Mr LOMAS: Yes. The point I make is that living in the community with a disability is very tenuous. It is like a see-saw. Things balance and you exist, you can do things. You can go out and you can engage in employment. You can travel or whatever it is you wish to do but if anything tips that see-saw slightly off-line then you have got troubles and that can be shoddy modifications, it can be care staff not turning up for rostered hours, it can be a whole host of things.

The Hon. MARIE FICARRA: Do want to expand on not being able to access case managers in a timely fashion?

Mr LOMAS: Case managers are your starting point. If you are living in the community and you need to get an extra service, or you need to modify an existing service, you need to go through a case manager who will then co-ordinate all of those elements. It is certainly my experience providing individual advocacy to people with a spinal injury, I have heard of people waiting three months or six months to get access to a case manager. This is even after the big allotment of case managers under Stronger Together which happened about two years ago but still did not satisfy the need. Particularly there was a lady who was living on floor one in a flat. She was discharged from hospital. She could not get down the stairs. The lift was broken. She was trying to see if she could just get someone to help her and put in an application to get a Department of Housing property on the ground floor and she could not get hold of someone. Her neighbour used to lift her up and down the stairs.

Mr KILLEEN: Home modifications are not just required when someone is trying to be discharged from hospital. Some people have a gradual disability who are not in hospital but are at home. So it will come to a stage where they might need assistance in the shower area and they need to have a modification of the bathroom. What happens sometimes is that they are also receiving care in the home and they will have a situation when the care service will say, "The bathroom is not big enough. We won't be providing service until you get the bathroom rectified" or "You now need" some piece for equipment "for us to assist you. We will not provide the service until you get it".

Often the equipment and the home modification and the care are all provided by the Government. You apply for the home modifications to this department, equipment from that department which is Health and not ADHC and the personal care support from ADHC. Instead of having a whole of government approach and fixing the problem in one go, some people have the threat of their service being withdrawn because the bathroom is not right, or they now need a piece of equipment that they are waiting six to 12 months for from PADP—Program of Appliances for Disabled People, which is run through Enable NSW, which is outside the terms of reference because it is not ADHC, but it is one of services that people with disability and older people will need to access possibly at some stage. Some people have difficulty trying to get support in the community when they are dealing with different departments from seeking funding. Often they have all got different eligibility requirements.

The Hon. MARIE FICARRA: The poor client has to try to co-ordinate all of that themselves. You say we need a whole of government approach that provides a central department for them to approach to co-ordinate the services? It makes a lot of sense.

Mr KILLEEN: It could possibly be only one application for everything, rather than separate applications with all the administration and bureaucracy that goes with that.

The Hon. MARIE FICARRA: Are inappropriate modifications are made that do not work or make life more difficult provided by so-called preferred tenderers? How do they get the job and keep it?

Mr LOMAS: I do not have the detail down to that level. I know that home modifications are not delivered directly by ADHC. They are subcontracted out to agencies and the agencies do the modifications themselves. What contracts they have with local brickies and chippies and people like that I do not know.

Mr KILLEEN: We will take that on notice and get back to you. We will see how it is done both from an urban and regional perspective.

The Hon. MARIE FICARRA: The process would be good to know.

The Hon. GREG DONNELLY: What is the current accreditation arrangement that operates with respect to advocates? How can it be improved?

Mr LOMAS: Currently it is up to all funded agencies to ensure that their advocates are competent at providing an advocacy service for individuals in the community. What that translates is "Are you able to go off and talk to people and get this sort of done?" The reason why we included it was that people have an expectation from their advocates when they go to them. They expect a professional service, a service to deal with their issue quickly, succinctly and get it resolved or at least move it on to wherever it can go logically from there. Now many people come into the area of advocacy because of goodwill. They come from a diverse array of backgrounds which could be of great benefit to how they provide advocacy. My background is on military. That means I go at advocacy from a certain perspective or in a certain direction whereas others may well come from other areas, ones who have been social workers or know all the ins and outs.

When I started this job I felt very, very uncomfortable that there was no requirement—I am actually federally funded—for me to have any formal training in advocacy itself. So I went and took a PIAC—Public Interest Advocacy Centre—course about advocacy skills and strategies. I felt uncomfortable that there was not a requirement in place and I really did want to have something on my wall that could say, "Hey, I can do this job" but there is not anything wider for that. I was thinking there are these great sort of bodies, I think, just one recently formed DAN—New South Wales Disability Advocacy Network. It is pulling together all the disability advocates in New South Wales, and why can't they work together to come up with some form of common training that will certainly give a degree of certainty to people contacting an advocacy organisation to say "I require support. Can you help me?" "Yes, this is how we do it".

CHAIR: Can I ask two things? First, could you comment on the issue of regions and the issue of choice and the difficulties in regional areas in having the ability to choose when there is an inadequacy in terms of the number of service providers and, secondly, could you give us some comments in regard to waiting lists—how they operate and how you access waiting lists?

Mr LOMAS: In terms of regional choice it is certainly very complex. Greg and I are in the process at the moment of writing up a regional issues paper where we are polling all of our members out in the regions and trying to get details coming in around that. But it certainly looks as if choice is not really an option just simply because there is not the number of agencies willing to go out there. Certain agencies that do have presence out in the regions at the moment are starting to pull themselves back because it just is not profitable and they cannot keep themselves going with the number of staff they need out there to provide a decent service. So in terms of choice I would not have thought there is really that much choice out there.

Waiting lists is always quite a thorny issue. Do ADHC keep waiting lists? I would assume that there is something out there that they do keep their hands on that enables them to forward plan. But I certainly know in regard to home modifications there are no waiting lists whatsoever. We have certainly been informed that all the people that are on the list waiting for home modifications that cannot currently be funded remains the concern of the local home modifications provider. That information is not required to be communicated from the local home modifications provider up to ADHC head office so that they can correctly forward plan a budget to meet that need and meet the people that are waiting.

Jokingly we have heard—it is bandied around in quite wide circles—that ADHC just do not want to keep waiting lists, it is not necessary for them to keep them; it kind of clogs the issue and clouds everything up. So, hey, some people out there need some support. That is how everyone jokes about it.

CHAIR: Have you got any suggestions for us as to how waiting lists can be better managed?

Mr LOMAS: Count your applications. Everybody that applies for a service you stick them on a list. You can actually see these things and monitor through to see how long it takes for a person to transition through. Once they are through that then they move on to another list which is receiving a service under this. So by then you can actually start to follow clients as they move through services. You can also see which services they go to, which services are required in certain specific areas in a larger amount than are in other areas. Data collection is very, very simple. This is a large government department receiving large amounts of money in funding; it should be able to count heads.

CHAIR: They need a man with a military background.

Mr LOMAS: I can count heads.

The Hon. HELEN WESTWOOD: Just going back to your answer about the need to coordinate services, do you have a view about what is the most appropriate model for the provision of services to overcome that problem? For example, a case manager, whether it would be brokerage where funding goes to a brokerage service in the name of the client and then services are purchased or whether it is direct funding to the person with a disability and then they purchase those services themselves. We have heard a little bit of evidence from various organisations about which model they think is the most enabling. I would be interested in your view on that.

Mr LOMAS: Both can run side by side. Individualised funding is great as long as the person can handle the work that needs to be done to make sure that those services are there and in place for them and they are monitored correctly and delivered in the way that they want them to be done. But also brokerage, if you receive individualised funding there is no reason why you cannot go to a brokerage agency and get them to coordinate all of the services for you and then provide you with reports on how those things are going.

Mr KILLEEN: On the first day of presentations from witnesses I know that Jim Moore made a comment about the attendant care program. I think he said there were about nine people who chose individual direct funding to coordinate their own services. That might be the case for that type of service because some people with high needs may not want to take on the role of having to coordinate that when they are dealing with a whole bunch of other things or they are busy doing a whole variety of things like working and do not need to have the onus of coordinating and recruiting and employing and time sheets and sick leave and super and all those things for their personal care staff on top of what they are doing. Personally I am very busy too; I am on the home care, I am not on the attendant care package, and I would not choose individual funding. I would leave it up to Home Care to coordinate the service. That is me as an individual.

I would say that there would be a lot of people out there who might receive respite services that do not require a complex personal care service but it is respite and I would say a lot of people would choose individual funding to purchase respite packages from services and to be able to pick and choose which service providers can meet their needs. There are currently some service providers that do not have a lot of staff and the staff they have are on a casual basis, and sometimes when the staff cannot meet their needs they subcontract out to another service provider. Those costs come out of the client's package or allocated funding, which means you get less bang for your buck because they are now outsourcing that, where if the client went to that other service because the one they were going to could not provide it, they might pay a lesser fee because there is not that extra fee on top of that. There are some benefits of having individual funding, particularly for that particular program.

CHAIR: That is an answer I have been looking for for some time. I think other Committee members have too and we are thankful for that answer; it explains a lot. Thank you very much for being with us this afternoon, it has been very helpful.

(The witnesses withdrew)

DIANA QIAN, Executive Director, Multicultural Disability Advocacy Association, 40 Albion Street, Harris Park, NSW, sworn and examined:

CHAIR: Thank you very much for being with us this afternoon. Would you like to make some opening comments before we go to questions?

Ms QIAN: Yes, I would. I must first of all apologise for not being able to provide a written submission before today. It is unfortunate that due to other commitments I was unable to do so. However, I have brought with me a document that MDAA, the organisation, published 10 years ago. Although being 10 years old the issues are still very relevant to the inquiry today so I would like to have permission to table this publication for the Committee.

Document tabled.

The publication is titled "Less Talk More Action" and I think that sums up really well what I would like to raise today. I think there has been an increasing awareness of the need to include people from a non-English-speaking background [NESB] with a disability in service delivery but very little has been translated into real action and therefore a very limited outcome has been achieved, at least over the last 10 years in my professional career. I would like to start by briefly talking about the organisation that I represent. The Multicultural Disability Advocacy Association [MDAA] is a statewide advocacy service and we were established about 14 years ago specifically to provide systemic and individual advocacy for people from a non-English-speaking background with a disability and their families and carers.

We receive Federal and State funding. Our individual advocacy program covers not only metro but regional areas such as Newcastle, Wollongong, Griffith and Bega. We are the only systemic advocacy organisation in the State that focuses on issues for people from a NESB with a disability. We are also a registered training organisation, so we deliver confidence training in the service sector. We have a program called Industry Development, which is to increase disability services, to improve service delivery for people from diverse backgrounds. That is MDAA in a nutshell.

There are a number of main issues I would like to bring to the Committee's attention. First of all, let us look at the numbers. What is the target group that MDAA is advocating for? People from NESB make up—first generation and second generation—about 36 per cent of the State's population. So we are demographically in New South Wales increasingly diverse. That proportion would be equivalent in the disability community, so more than a quarter of the disability population are either born in a non-English-speaking country or are second generation NESB. We do not see that proportion in the people who access disability services. We see about 5 per cent of ADHC service users from NESB—that is according to our estimate. Data is very limited around looking at the intersection of cultural heritage and also disability.

So there is a level of underutilisation of specialist services and we think this is due to a number of reasons. First of all, it is the lack of access to culturally appropriate information. If you do not know the service is there then you would not be able to inquire about it, you would not be able to get yourself onto a waiting list and you would not be able to get access to it. So the vast majority of people from NESB with a disability cope with their needs within the family context and they are very isolated.

Many of us come from a cultural background where disability services are not a concept we are familiar with. Disability in itself is a concept that is not universal; it varies in different cultures. Some cultures do not have the word "disability". So when you are looking at provision of information it is not about translating what ADHC provides into a brochure, into Chinese, Lebanese, whatever. It is not that simple; it is much more complex. It is negotiating cultural references, negotiating between different cultures. It is not only that there is very limited written information, translated information about specialist and disability services, most of the translated information available is not inadequate—they are inappropriately translated.

If people by chance find out about ADHC services then the next step will be to go through the intake-referral system and that occurs in a very ad hoc way. People can try to ring the intake-referral line but we question the utilisation of some interrupting by ADHC staff. I have personally called a number of ADHC intake lines and started to speak in Chinese and the poor staff person on the other end of the line starts to talk louder and louder. Actually I am able to respond effectively to manage the call. After five minutes I put an end to the misery and let them know I wanted to see how responsive the system might be.

The Hon. TREVOR KHAN: You are very unkind.

The Hon. MARIE FICARRA: No, she is being very kind actually.

Ms QIAN: We identified a bit of discrepancy. We come into contact with people from NESB with disability on a daily basis—we support 400 people per year. People come to us often as a last resort, because they have exhausted all options of trying to get into the disability system. I am sure you have heard from other organisations that it is a maze—it is not easy to navigate—and if English is not their first language you can imagine the frustration. We hear a lot of real experiences of people trying to make contact. Unfortunately a lot of people after the first phone call if they do not get through they give up. We identified a trend where the service users from NESB with disability tend to be in the high-end age group and they tend to be in crisis.

Young people, children with disability, young families with children with disability, are not getting the benefit of early intervention services. There are students from NESB with disability going through the school system and when they finish school they fall off the face of the earth, they drop off. Because in post school programs from AHDC we often find a very low utilisation of post school programs, which means school leavers from NESB with disability are not being transitioned to either vocational training, employment support or community motivation. There is also very low utilisation in support accommodation services. You can see an increase above 40 in the CALD group utilising AHDC, and often they are at the end of their tether. The carers, usually family members, acquire disability themselves because of long-term care.

Once people got into the service—so imagine they got through the intake-referral line, they actually got through to a service—then there is a huge issue about those services being able to be responsive to people's individual needs. That could be their linguistic needs, their religious needs, or it could be their cultural needs. In the disability service sector there is still very much focus on managing disability and not supporting people who happen to have disability. Very single dimensional; very narrow. That is why it is so difficult for MDAA to push the needs of people from NESB with disability because we are expecting people to broaden the way they see their clients and see something different other than just their diagnosis. We come across examples of people in accommodation respite services with their religious needs being ignored, people's dietary needs being ignored, interpreters not used when having client meetings, or individual planning meetings are not conducted in an appropriate or an inclusive way. There is a whole range of examples where we see the system unable to work effectively with diversity.

There is a lack of benchmarking and a lack of monitoring for equity outcomes. Stronger Together was very exciting when it came through and it was going to be the solution to all our problems but, unfortunately, five years down the track and Stronger Together in MDAA's view has not delivered for people from NESB because the more money you invest into a system that is inequitable you are actually increasing the inequity because the people from NESB are not getting the benefit of the additional funding. We are not even getting onto the waiting list for the additional placements. There are some small pilot projects in Stronger Together but in comparison with the amount of funding it is hugely inadequate to address the needs of people from NESB with disability.

CHAIR: Can you be more specific than your general comment that it is inadequate?

Ms QIAN: I will give you an example. In Stronger Together a drop-in service, a pilot program, a drop-in accommodation support project, 20 packages for metro south. Well 20 NESB-specific packages compared with how many accommodation places, 100s of accommodation places being established as a result of Stronger Together, so if you look at the proportion of people from NESB with disability in the disability population then you would expect some proportionate allocation of packages earmarked for people from NESB. The 20 packages, you know, out of 100s of places is why I said it is inadequate.

I also want to touch on ADHC policy framework. The experience of MDAA in working with ADHC we have found that individual staff from ADHC are quite responsive and there seems to be a commitment from ADHC to improve service access for people from NESB but that commitment has not been translated into broad, systemic action. We do not see broader policy framework from ADHC that addresses the needs of disadvantaged groups, for example. We do not see contracts being managed, funded services being managed and being held accountable, data being collected about indigenous access and NESB access but we do not know what has happened to that data, it is not made public. We do not know what ADHC does with the data. We do not know whether the organisation is being held accountable if they really have no clients in their service that are actually from those backgrounds. There is a lack of investment in research to find out better ways of working with people from diverse backgrounds. From a quick look at ADHC's website you will see a long list of research projects commissioned. Out of a very long list you see two that look at cold population: one was on dementia and another one on HACC, none on disability support.

On a slightly more positive note, I think there is increasingly penetration of a level of awareness in the collective consciousness of ADHC and the disability sector. MDAA has certainly been invited to work with ADHC, work with other services, been invited to provide advice, and we have been requested regularly to conduct consultations with the NESB disability population. So there is certainly an acknowledgement from ADHC. There has certainly been a request for meaningful information but we actually do not know where the advice goes. We conduct consultation on behalf of ADHC, we provide ADHC with that information but I do not know where it goes. People who I conduct consultation with have come and asked me what happened to the input they provided, because on the ground people have not seen a lot of real changes.

I would like to raise a list of recommendations what MDAA would like to see as outcome from this inquiry. We would like to see free access to interpreters be provided for ADHC services and funded services—something like the Health interpreter pool. So a pool of interpreters who are trained with sector knowledge be available freely to services. At the moment it is a user-pays system and they do not use interpreters and at the end of the day it is the clients who miss out—so an extension of the Health interpreter pool. Also ADHC needs to develop translated material in partnership with multicultural communities. At the moment there are only about two or three pieces of information on the ADHC website available in community languages and we would like to see a lot more of that.

We would like to see a social marketing campaign promoting the rights of people with disability and promoting the concept of rights and services to multicultural communities. We would like to see ADHC incorporating diversity measures and outcomes in all of its program guidelines, not just as a tag-on. We would like to see ADHC develop and implement equity benchmarks, not just access data but look at quality of service outcomes for people from a non-English speaking background [NESB] with disability as you benchmark. We would like to see ADHC build its internal capacity, integrate diversity in its core planning and invest in its staff's capacity to work with people from NESB with disability. We would also like to see ADHC invest in the sector capacity to be more culturally competent and more capable of working with diversity. There is an opportunity in the recently released $17 million industry development fund and we would like to see cultural competence as a priority area in the allocation of that $17 million. There is my wish list.

The Hon. MARIE FICARRA: That was really comprehensive. In the story of migration to Australia there are now second and third generations of the first set of migrants, such as my parents and family, and they do not see themselves as non-English speaking, they are just Aussies. Do you see a variation? Should we be channelling more services into the recently arrived migrants, particularly the refugee element who are a very socioeconomically depressed set of migrants that come from the subcontinent and Africa? Do you see that as a greater need? I know that the Italian community has Co.As.It and a number of service providers and I imagine the Chinese community are pretty good at doing this as are other older established migrant organisations. What do you see as the variety in the NESB area, which is a big area?

Ms QIAN: I hope I will not be seen as too greedy if I say that both needs are important. They have very different needs if you look at the pattern of migration. People from the more established communities—Italian, Greek, Chinese—have more services established within their communities but there is still a lot of stigma attached to disability. I certainly know about that in my own community. As a Chinese person with disability I may not choose to use a Chinese service because of the level of stigma in my own community. There has not been a disability rights campaign in multicultural communities. For people who are second or third generation there might be no language issue but we still have our cultural heritage and that needs to be appreciated in mainstream services because a lot of those people might choose to use mainstream services and those services need to be responsive to our individual choices.

I have been living in Australia for 22 years but I still have a very strong connection to home country background and when I access services I would like my cultural heritage to be respected, or at least be made to feel welcome. I agree there is a huge need to support our refugee communities and the newly emerging communities because the social and financial capital in those communities is very low. They are starting from a very low point. My short answer is we need to do both. We need to strengthen mainstream services and no longer see people from NESB with disability as a special interest group or a tag-on. We need to have the choice to go to a mainstream service and feel included and part of the mainstream because Australia is one of the most diverse countries in the world, so diversity should be mainstream. I also respect people's choice if they want to use an Italian service or a Chinese service in their own community. It may not be my personal choice. We need to provide those services but we are not going to achieve systemic change until we make the mind shift that mainstream is not Anglo, mainstream is diversity.

The Hon. MARIE FICARRA: Absolutely. That is a great point. I agree with you that we have to do a better job at communicating people's rights and their access to services. Do you think there is still a mindset in a lot of ethnic communities that there is a stigma associated with disability and, secondly, that the individual and the family should be able to cope—you should be able to rely on your family to cope, you should be able to rely on your children or your immediate family to interpret and to take you places and look after you. There is an attitude that people are expected to cope and cannot be a burden on this society that accepted us in the first place. Is that a big issue with some of the older communities?

Ms QIAN: Absolutely and it is on both sides. Every day I talk to service providers and a lot of them will say, "Why do we need to provide a service to people from NESB? Wouldn't they prefer to be looked after in their family?" There is a myth in the service sector that people from NESB with disability do not want to access services and would rather be left alone. That is an easy justification for the low access rate. There is that myth and the service providers send out that message. Families that have migrated often do not have the support of extended family once they migrate. We do not migrate as a bloc. I came here with my parents and my extended family were all left behind.

The family's capacity to deal with issues is very limited after migration to the new environment. They might feel that they have to cope as a community expectation, they might fear government authorities or they do not feel they can make contact with services. We have also come across families that do not want anyone to know they have a family member with disability. Twenty years later you discover somebody who has been hidden away in the family home. All of that is complex. It is about individuals' understanding of disability, individual identity, family identity and cultural context and the level of support they perceive they will be able to have. There are different layers and it is quite a complex issue. It is not straightforward.

The Hon. MARIE FICARRA: In terms of awareness campaigns, how much raising of awareness of people's rights to basic things such as disability services is there in ethnic newspapers, television and radio? How much has been done?

Ms QIAN: There is not a lot of awareness. Once in a blue moon you might have an article in a community newspaper about disability. MDAA certainly has been working with SBS radio and community media because no investment has been made and there is no conscious effort on the Government's part to invest in a social marketing campaign. All of that has been very ad hoc. MDAA recently completed a project which won a National Multicultural Marketing Award, which was to develop an information kit targeting families with young children from refugee backgrounds. We looked at the balance of accessibility. We made a DVD and a booklet with very easily accessible language and had that translated. The DVD was also dubbed. We worked very closely with the media in those refugee communities and involved families and workers in those communities to help promote the kit. That is one strategy of addressing the enormous disadvantage in those refugee communities. The information was about going to school. We kept the message very simple. We want to communicate to those communities that children with disability are entitled to go to school. We believe if we get those kids into a school system and into early intervention services they will have a much better chance later on in life to enjoy what life can offer. But if they are isolated and kept in the family home they end up in a crisis situation when parents are no longer able to care for them.

The Hon. HELEN WESTWOOD: I am wondering whether the culturally and linguistically diverse [CALD] disability community is younger than the general disability population because of Australia's migration policies on disability. I am assuming that people, other than the refugee population, are born here with a disability or come when they are very young and before it is diagnosed or they acquire it. Do you have any sense of that population?

Ms QIAN: Yes, we do. Traditionally the census did not include a question on disability. The 2006 census was the first time there was a question on support needs. The disability census does not include a lot of questions about country of birth, language spoken or heritage. You are looking at two sets of data. They do not ask the same questions so you cannot correlate them. MDAA and the National Ethnic Disability Alliance [NEDA], our national counterpart, have both done a lot of work on data. Because of the migration policy people with disabilities are usually excluded. They acquire disability after they enter the country, often due to involvement in unsafe workplaces and manual labour. You see a spike of disability prevalence over the age of 40 or 45. There is the other cohort at the young end; that is, the ones born here. There is not a huge proportion in the middle.

The Hon. HELEN WESTWOOD: You have identified the problems facing culturally and linguistically diverse people with a disability in accessing appropriate services. Do you think there is a role for CALD and bilingual workers within ADHC and non-government organisations? Are there many of them? Are the service providers aware of them and do they recruit them?

Ms QIAN: MDAA has been pushing that strategy for a while; that is, increasing the diversity of the workforce. I am not sure about the human resources data in ADHC. However, we have been working with ADHC and disability services looking at recruitment strategies, staff training, policies that would utilise bilingual and bicultural staff and seeing staff from diverse cultures as an asset to the organisation. We work with them around developing diversity management plans for their organisations. It is starting, but it is very slow. MDAA receives very limited funding to do this work. We cannot really be influential to the point we would like to be to make broad changes. However, we have seen an increasing utilisation of bilingual, bicultural workers in the organisations we work with. I sound a note of caution with regard to strategies: It is not as simple as recruiting people from NSB but also developing their capacity to work with diversity. Someone from a Chinese background might carry prejudices from their culture about disability. Similarly, just because I am Chinese does not mean I am not racist.

The Hon. HELEN WESTWOOD: I was going to go further with regard to that theme and the stigma about disability. Is that a barrier to recruiting some people from CALD communities? That is perhaps linked to community education and urging CALD communities also to value diversity. Have you done any work on that with other diversity organisations? Do you know of any work that has been done that we could look at and utilise?

Ms QIAN: ADHC is funding a recruitment strategy involving a series of TV ads. Some target multicultural communities. However, as you have identified, if the level of awareness in those communities is low about disability rights, we would not get the benefit we want from that marketing campaign. Disability work would have been seen as less attractive in those communities. You need a two-pronged approach. MDAA did a project two years ago called "Opening Doors". We worked with 10 different communities and brought together workers from those communities. We engaged in a conversation with them about disability and asked how they saw disability in their community. We explored a range of cultural issues around disability specific to those communities. We then produced 10 booklets on cultural perceptions of disability and how disability is perceived here. We provided those two perspectives.

Interestingly, people were very open with us about the stigma in the beginning. After we wrote up what they told us and then gave it back to them they asked us not to publish it. People were reluctant to be open about it in their own community but they were open with us in a room. After we wrote it up and said we would publish and distribute the information people wanted to distance themselves from it. People have a lot of pride and identity attached to their cultures. I am no different. A lot of work still needs to be done to build trust with those communities so that we can have open dialogue about difficult issues like disabilities. It is a long-term community development task.

The Hon. GREG DONNELLY: Thank you for appearing. You might be able to help us with the issue of carers and government support for them in the context of multicultural communities, particularly with regard to the future. What do you think governments need to do for carers in the communities you represent?

Ms QIAN: First, the word "carer" is problematic in multicultural communities. Again, it is not universal. Often family members who provide care will see that as part and parcel of being a mother, wife, husband, partner, brother or sister; it is part of being in a family support relationship. They do not necessarily identify themselves as a carer or even want to adopt that label.

If you structure a service system based on the expectation that people need to adopt a label before they become eligible for service then you exclude a range of people. If someone fronts up for services and they say they are a carer they will automatically be channelled into a range of carer support services. If they do not do that they might be excluded.

Families often want to be involved in service planning and delivery for their family members with a disability. The way that decisions are made in the family varies from culture to culture. Services need to be sensitive to that. Trust must also be established with carers or family members to ensure that they know that the cultural and religious needs of their family member will be respected. Sometimes carers from NSB would be reluctant to use a respite service or would refuse service because that trust has been breached. If you are looking at supporting carers in those communities you first need to look at how the system can best support people with a disability. Only when they are supported can the word "carer" become redundant. They can have a meaningful family relationship with a person with a disability. They can be who they are—mother, wife or whatever—rather than purely basing their relationship on caring. That is not how we like to see people with disability supported in our society.

The Hon. GREG DONNELLY: Thank you for that. That was a very detailed answer. We have had witnesses give evidence about a self-managed funding model for individuals who are disabled. Your nodding suggests you are aware of the concept. Would you care to share your thoughts about that concept, its strengths and weaknesses and its application in the future?

Ms QIAN: The terms "individualised package" and "self-managed model" are used interchangeably. That is the way to go. We think that for service to be culturally competent and responsive to people's needs service users need to have more say in the way they are delivered. They need more power in that relationship. If you decide on a model, often it can be quite restrictive and people's cultural needs might be excluded.

I will use group homes as an example. You share accommodation with four or five other people and the needs of those individual residents must be negotiated. As a result it is less likely that your cultural needs will be met in that environment. A self-managed support model, where the individual can have a choice about where they live, either on their own, with a flatmate or with their family, and have full control of who provides that support, will ensure that their individual needs are met. They have choices and the power to design the support that best suits them. We have been advocating for that for a long time.

The ability of individual families to manage funds would be varied, so you would be looking at a spectrum. You have people who want to have full control of the funds, or do the recruitment, the planning, the rostering and all of that. But you will also have families that have limited capacity to do that. So, you need to have brokerage, the kind of intermediary support centre, to support people to manage that.

CHAIR: Who makes the decision on capacity?

Ms QIAN: Sorry?

CHAIR: You indicated that there were varying capacities?

Ms QIAN: Yes.

CHAIR: Who makes the decision on capacity if you give someone who does not have the capacity a self-managed model, how does that help them?

Ms QIAN: I would hope that would be worked out before the funding is given.

CHAIR: By whom?

Ms QIAN: There needs to be a negotiation assessment process, where the family can have a say and be able to identify what capacity they have to manage funds and to what degree.

CHAIR: Who will make that choice? Is it the consumer or a provider to the consumer who happens to be a family member who may have different needs and wishes than the client? We are going down some very interesting paths.

Ms QIAN: We are having very interesting discussions. We advocate for the rights of people with disabilities. Our argument is that the person with disability needs to have that decision making.

CHAIR: Have the right to choose?

Ms QIAN: The right to choose.

The Hon. TREVOR KHAN: And make a mistake!

Ms QIAN: Well, we all make mistakes. That is how we learn, as human beings. Part of being human is to have the opportunity to take risks and make mistakes.

CHAIR: I boldly assume that society's role is to actually minimise the risk. For example, I have complete control over a person I employ here, but I do not employ that person. I am trying to come to grips with minimising the risk that a person might have without limiting in any way their choice.

Ms QIAN: It has to be a balance and compromise, because we are talking about taxpayer's money as well. So, as much as I would love to have $10,000 to experiment with, there is a degree of responsibility that you expect from people. There has to be a negotiation process between whoever makes the decision of allocation, either ADHC or a funded service, and individuals.

CHAIR: With the objective being to maximise the choice of their user?

Ms QIAN: Absolutely. At the moment you have a supply-driven service system: these are the products we have available, funded, and people with a disability can choose only within what is available. Now we are looking at a more market-driven approach in light of the Productivity Commission inquiry, so that users as consumers can have more choice. As I said, we need to look at a balance in that.

CHAIR: Yes, as long as we do not get mixed up with free choice and the freedom to choose.

Ms QIAN: That is a myth.

The Hon. TREVOR KHAN: Well done!

CHAIR: I do not know whether it is a myth, I am glad you think so.

Dr JOHN KAYE: Chair, I am mindful that we are short on time. I will ask a brief question. You mentioned in your wish list, which was excellent, the issue of free interpreters. That is very important and something that many in the community would be mindful of, but you talked about raising the capacities within ADHC. Briefly, in what way how do those capacities need to be improved? How would you go about doing that?

Ms QIAN: Yes. First of all, strengthen the diversity unit in ADHC.

Dr JOHN KAYE: Strengthen, as in provide more people to it?

Ms QIAN: Provide more people to the unit, so there are more people to drive changes internally. The diversity unit was established five or six years ago, and it went through a fairly rocky journey. It went up and down in the ADHC system. Two years ago, it was elevated to a quite high level, but now it is demoted. Where the diversity unit sits in the ADHC hierarchy is really important, because that determines how effectively they can drive changes. Secondly, implement the diversity plan that was developed by the diversity unit. That plan has been in the making for quite a long time, and we are yet to see the plan being launched and implemented.

Thirdly, incorporate diversity management into the core business of ADHC—there is more rhetoric than real action. Fourthly, revise all ADHC guidelines, so that they incorporate the principles on social inclusion and diversity. Also, staff training for ADHC staff, training for policy makers on how to develop policy that is inclusive and culturally competent and also training for on-the-ground staff on how to work effectively. For example, train all their front-line staff in their intake referral system on how to work with interpreters. How to dial an interpreter when one is needed. Have an audit of the internal referral system to make sure it is accessible. I could go on for ages. There is a very long list of things that ADHC can do.

Dr JOHN KAYE: Would you provide the Committee with a written list of things that could be done inside ADHC to raise its diversity capacity?

Ms QIAN: Yes, I need to do that tonight. Tomorrow morning I am hopping on a plane to China. Yes, I will do that.

CHAIR: Thank you for appearing before the Committee today. The Committee will take a short adjournment and reconvene at 3.45 p.m.

(The witness withdrew)

(Short adjournment)

ANITA FISHER, Senior Manager, Client Programs, Northcott Disability Services, 1 Fennell Street, North Parramatta, and

KERRY STUBBS, Chief Executive Officer, Northcott Disability Services, 1 Fennell Street, North Parramatta, sworn and examined:

ELIZABETH FORSYTH, Manager, Service Development and Government Relations, Northcott Disability Services, 1 Fennell Street, North Parramatta, affirmed and examined:

CHAIR: Would you tell us the capacity in which you appear before the Committee?

Ms FISHER: I am Senior Manager, Client Programs, Northcott Disability Services.

Ms STUBBS: I am the CEO of Northcott Disability Services.

Ms FORSYTH: I am Manager of Service Development and Government Relations at Northcott Disability Services.

CHAIR: Would you like to make an opening statement to the Committee before we proceed to questions?

Ms STUBBS: Briefly I will make a couple of comments. We have welcomed the partnership with the non-government organisations that we have seen and Ageing, Disability and Home Care [ADHC] over the last number of years. We think that has been very valuable. We also welcome clearly the extra funding that has been given under the Stronger Together Program. The things we want to say are basic clear constructive suggestions for the future for our clients. The four key areas we particularly would like to draw your attention to, but we are happy to answer questions that you have, clearly on our submission are issues around eligibility and the fact that eligibility is somewhat restricted for people with disabilities to ADHC services and sometimes ADHC-funded services. There are particular issues for rural and remote people with disabilities and how difficult that is. Northcott provides services across the whole of New South Wales, so we are particularly aware of some of the issues for people in rural and remote areas. There is the issue of transition funding for people moving between various stages of their life—from early childhood to school, from school to adulthood—and there are the issues around single point of entry into disability services. They are the four things that we are particularly concerned about.

The Hon. MARIE FICARRA: Can you expand on single point of entry?

Ms STUBBS: I will talk briefly but I am happy to defer to either of the other two because they have much more experience. Really it is the issue of access to services. In many cases there is no single point of entry. It is a bit of a hit and miss to find a service or to find the right service and to get what you need as a person with a disability.

Ms FORSYTH: I do not think it is a question of a single access point. We are not talking about one place but one system whereby you access services. Currently people might call up ADHC Information Referral and Intake. They might find information about ADHC will be referred to a non-government organisation or they might just come across a non-government organisation and speak to them about what services they can offer. Sometimes the service that people get then is not reflective of what might be available across the system. We are suggesting a system that is based on having a standard system for accessing disability services. Whether they are provided by ADHC or the non-government sector, having one system would help all people have access to the same information about what services are out there.

The Hon. TREVOR KHAN: What does "one system" mean?

Ms FORSYTH: I cannot answer as to how that would look in practice except that there are currently some services that try to do this. For example, in the respite system there has been a need to try to establish a central way of families accessing respite and the establishment of local respite coordination groups. A family might be referred to a service. That service might not be able to provide respite to that family because they are full or it does not meet the criteria for that particular service. Instead of just saying, "Here is the number for five other different organisations", that referral is taken to a coordination group meeting of all the respite providers in that area and it is discussed as to who is best placed to be able to take up that service. If no one is able to take up that service that is a recognised identifiable point of unmet need in that community.

Ms STUBBS: Similarly in Western Australia there is a system whereby they have funded positions on a local government basis. Those positions, which I understand are funded through the Western Australian Government, gather together the information and are referral points for people with disabilities about what is available. They are able, therefore, to be the source of information that people can come to and find out how they can get referred to various services, rather than having to do the telephone tag or doorknocking everywhere to find the service for them, even if they know where to start.

Ms FISHER: We have had one very good example of a working relationship with ADHC and other non-government organisation partners around the setup of the Intensive Family Support services in the metropolitan north region. We worked in establishing the services and then having a network. It was the Spastic Centre, ADHC and ourselves. Initially there was discussion around ADHC being the only central point of referral for families to the Intensive Family Support system. There was discussion amongst the non-government organisations that it would be better in terms of enabling greater access to families in crisis if they could come through any of our services and then we would bring the referrals to the panel meeting. There is an intake panel, but the point of access can be through any of those sources. It is working very well.

CHAIR: As a matter of clarification, are you talking about the ADHC vacancy management system?

Ms FORSYTH: My understanding of the vacancy management system is particularly in reference to accommodation. We are not talking about that particular system.

The Hon. MARIE FICARRA: In other words, it is making it more user-friendly and bringing a whole-of-government approach and a whole-of-disabilities sector approach rather than having the client trying to access all the different services and becoming frustrated and disillusioned and going away and having their needs are unmet? There must be a great deal of that happening?

Ms STUBBS: Not even getting there in the first place because they do not know there is a service available to meet their needs. We still come across people in rural and remote areas who have been existing for a long time with no services because they did not know there were any. There is a real need for information to clients and easy ways for them to find out what is possible. I suggest Western Australia has a model that is worth looking at.

The Hon. MARIE FICARRA: Do they also cater in that coordination for non-English speaking backgrounds?

Ms STUBBS: I do not know enough about it to know, but I would hope that is the case.

The Hon. MARIE FICARRA: You mentioned also that one of your areas of concern is the transition of disability services from one phase of life to another. Can you expand on that? It is obviously not being coordinated optimally now.

Ms FORSYTH: There are differences in the types and amounts of services available across the lifespan. Families might find they get a lot of intervention at an early age. Then when they have to transition to school, there may be a change in the system as to how they receive support. It might not be the same; it might not meet their needs. It can be a confusing time. The other time that is particularly difficult for families is the transition out of high school and the move from accessing children's or paediatric services, whether that is through ADHC or through the health system, to ADHC services as an adult. It is a particularly difficult time for families to go through that transition but also to try to understand a completely different way that funding might operate, for example.

Ms FISHER: Also, transitioning from being an older person with a disability into the aged health care system along with the aged care population would be another transition.

The Hon. MARIE FICARRA: Would you please repeat that?

Ms FISHER: I guess I am thinking about the clients I might have worked with in our adult team who have a disability and who would probably identify as a person with a disability for most of their life, and at the point of 65, I imagine, they are transitioning to a system now being regarded as an aged person, so it is another point of transition where things change for them.

The Hon. MARIE FICARRA: The Government is moving towards the second phase of Stronger Together. How much additional funding do you believe is required? Can you put a figure on it?

Ms STUBBS: That is a really difficult question because we are clearly not actuaries. We do not know how much unmet need there is but I would have thought at the very least you would want the same sort of increase in funding that you had in the first phase; additional because there is still a great amount of need out there. Certainly from our perspective, as we talked a little about eligibility criteria, people with physical disabilities are rarely part of the general eligibility criteria so there is a lot that they do not get. It is going to be an issue for the Government as to what it can fund and what it cannot quite clearly. There are not too many service providers that we know that would not be looking hopefully at a national disability insurance scheme to work through some of these issues in the long run. I do not think we can give you a figure. I think there are better people to give you that.

The Hon. MARIE FICARRA: Your submission calls for more transparency in the level of funding for services. What do you mean? Why do you call for it?

Ms FORSYTH: For us that is in relation to unit costs for services. So how ADHC determines a particular type of service might be allocated a particular level of funding, particularly when you can look at really comparable services that have very different unit costs but are providing the same kind of service, possibly in the same location. The other issue for us is about our historical programs and what they might have been funded at and knowing how ADHC determines unit costs and outputs and levels of funding would place us in a better position to be able to go back to ADHC and say, "Based on how you worked this out, this is the outputs that we should be achieving for this amount of funding".

Ms STUBBS: We are not suggesting that there is anything nefarious going on. We are suggesting that it would be easier for us to understand how to provide the right sort of services in the way, if there was more transparency in how that was calculated. I think a lot of it is an accident of history and changes over time in different sorts of programs.

Ms FORSYTH: I think if there was more transparency about the process that would help non-government organisations benchmark the services they are providing and the costs that those services are.

Ms STUBBS: Because there is really no way to measure across the industry that I can see of how efficient we are. There is not a benchmarking system, and that would be very useful, I think, for the whole of the industry.

The Hon. TREVOR KHAN: I congratulate you on the way that you have presented your evidence so far, at least from my perspective. It is quite different watching some of the NGOs and how, for instance, the three of you interact with us, compared to ADHC where there is only talking head and a cast of thousands sitting at the table. There is a spirit of interaction that I find stimulating in that respect.

Ms STUBBS: I think because I know my limitations.

The Hon. TREVOR KHAN: I will not say anything. Do you know whether the unit cost that is applied for the provision of a service that is quoted to you is the same as the unit cost that is specified to another NGO?

Ms STUBBS: I am sure it is but I do not know. There are published tenders so we do then.

Ms FORSYTH: It would depend on the information provided in a tender. So for an accommodation tender you might be given the maximum amount of funding that you can ask for in your tender. You then determine, based on your staffing model, the outputs which give you a bottom line unit cost, but essentially that information is available to all NGOs that are tendering for that.

Ms STUBBS: But if it is a community participation program there is a certain amount of money per client, and that is freely available. That would be the same for every NGO. It depends how you then provide your service against them. It depends on the service. Clearly different NGOs organise themselves differently so they may be able to deliver things differently. It is more about the tendering costs, and how it is worked out, what it is worked out on, what the principles are.

Ms FORSYTH: The other experience for us has been the shift from having outputs based on number of service users to shift into hours of service. In doing that exercise for us to have had the information as to how ADHC worked out how many hours of service that funding equated to would have been useful information.

Ms FISHER: And that has only just happened recently with some of my programs, and happened without us knowing that it happened. We met with our project officer and got told that they had recently changed the hours. We are in the process of working out really what that means in practice and whether it is reasonable for us to meet those hours. When we originally negotiated our tender it was reasonable based on the number of clients, service users.

The Hon. TREVOR KHAN: On page three of your submission you say "ADHC would cease to provide those service which are able to be provided more efficient"—I take it, it should be "should cease"—"and effectively by the NGO sector and use the savings realised in increased services." What services do you believe can be more effectively and efficiently provided by the NGO sector? Why do you believe that is the case?

Ms STUBBS: Firstly ADHC tells us, and has told the NGO sector quite consistently, that there are a number of services that we provide more efficiently and they have gone into moving out of those services as much as possible. So they have started moving out of their day programs, they are beginning the process of moving out a lot of their accommodation services, respite services, I think, and there are others. So that has been part of ADHC's own movement because it recognises the cost of providing services is cheaper in the NGO sector than it is when you have the whole machinery of government around you, and a whole range of other things that you need to do, apart from just service provision. How much cheaper it is, I do not know, but clearly there is some work around that that ADHC itself has done because it gives us that information. Clearly there are other things where it would be very difficult for the NGO sector to provide the services. They would largely be, I think, the very high needs specialised areas and probably some of the forensic areas where it is very difficult for NGOs to be involved in the same way that the ADHC can be. But they have been working through that process.

Dr JOHN KAYE: Would you explain what you mean by "forensic areas"?

Ms STUBBS: Where they need to keep people locked up, prisons and those sorts of places is what I am talking about. Clearly that is not something that you are going to get NGOs doing.

Dr JOHN KAYE: Hopefully not.

Ms STUBBS: Nor would we want to. There may be some very high support areas, people with particularly challenging behaviours, for example, where it may be difficult for the NGO sector to provide the same services. But I cannot answer in detail but I know ADHC is working through that process itself.

The Hon. TREVOR KHAN: How big is Northcott?

Ms STUBBS: We have about a $30 million a year turnover, about 500 staff.

The Hon. TREVOR KHAN: Are they full-time equivalents?

Ms STUBBS: No, it is about 320 full-time equivalents. We cover most of the State.

The Hon. TREVOR KHAN: In your submission you refer to an argument that there should be a differentiation in unit costs between what I take it to be city, rural and regional areas. Is there some sort of funding model or point of differentiation that would identify between city, rural and regional? If so, what is that differentiation and why?

Ms FORSYTH: I guess it comes back to the issue of unit costs again and if there was some clear information about how they were calculated you might be able to better develop a model. We certainly have not developed a particular model but we can talk to the additional costs of providing services in regional centres. They are associated with large geographical regions to cover, so a long time spent and lots of resources put into travel, or possibly accommodation for staff to service large areas that are funded at the same level, as the same service that we have in a metropolitan area, for example.

Ms STUBBS: Quite often travel costs are not able to be counted in service costs. Say, if you have a certain number of hours that you need to deliver, you cannot count travel hours in those hours in the outputs so there are some real difficulties around meeting some of those requirements.

The Hon. TREVOR KHAN: Would you differentiate a difference in unit cost for the provision of a service in a centre such as Tamworth compared to Sydney? Would it be that you are looking at the provision of a service, say, in Broken Hill where you are covering a large and dispersed area?

Ms STUBBS: Our experience is if you are starting a new service in a new regional location—and we have an office in Tamworth—there is not any funding to start an office in a region so you have to cobble together a number of programs that may give you enough recurrent funding to run an office there. We normally would put in an amount of our own money for start-up costs, accommodation, for capital. Quite often we would go in at a loss because we bank on the fact that over time we will be able to pick up enough services to have a critical mass to enable us to run and break even. Rarely would you just service the Tamworth area.

From those offices you are mostly servicing as far out as the Queensland border because your clients—you are talking about a smaller number of clients clearly in a large geographical area and they will not necessarily be all sitting in Tamworth. They will be in the surrounding New England area so you will still need your staff to be driving, maybe three, four, five hours to see one client and then back again. I came from Health and it is not like setting up a hospital where people are coming to you. Our model is we are going out to them in many cases. A person with a disability who has to travel to a regional centre is often even more difficult because it is hard for them to get the transport. It is a fairly complex economic model to make it work.

CHAIR: Management and administrative issues are very complex. You could set up in an area that encompasses regional and remote and you are a deal larger than say, a home care service branch?

Ms STUBBS: Yes.

CHAIR: So the philosophy that NGOs are more localised is not always the case?

Ms STUBBS: If there is an NGO there. If we are setting up in one of those areas we are using local staff, we are employing local staff. Our philosophy at Northcott is to work in the community. For example, we set up a branch office in Moree last year with one program. It now has three programs but there is still a way to go.

CHAIR: Logistically do you see any difficulties in teaming up with other organisations to have a regional management administrative structure?

Ms STUBBS: Not at all. In fact, we encourage working with other organisations as much as we can.

CHAIR: On page three of you submission you highlight the difficulties of attracting skilled employees. The Committee has also heard evidence from National Disability Services New South Wales regarding the Care Carers Program. What action is your organisation taking to attract and train skilled staff within the constraints about which you talk in cobbling together management administrative structures?

Ms STUBBS: From our perspective we have our own Enterprise Agreement, own collective agreements, so we do not operate under the SACS award, for example. We have in the past 12 months or two years put in a new pay scale for allied health workers, for therapists as a way of keeping and promoting and attracting allied health staff who are in particularly short supply. To obtain allied health staff we compete with Health, the private sector and a whole lot of people. There are not enough of them to go around in New South Wales anyway. We do a lot of training for our staff and we have reduced our turnover to under the industry average in the last 12 months. So we have put a lot of time and effort into putting in programs that will attract and retain good staff, but there is a shortage particularly of allied health staff and disability support workers, who are the other large group who are very badly paid, they are poorly paid, and in that area we compete and industry competes with retail, with tourism, with other areas, and a lot of the problem is the pay rate.

CHAIR: Did you have any input into this comparison of add-up costs per unit or unit costs and the unit costs that you have where they say that you are cheaper and in some areas they are dearer? Did you have any involvement in that?

Ms STUBBS: They get all our information. All our information goes into ADHC. So input in terms of providing information yes, but we have not been involved in the analysis.

The Hon. GREG DONNELLY: The issue of the numbers of NGOs is something that has come up from other witnesses. We understand that there are around 460 in the State.

Ms STUBBS: I would have thought there were about 900.

The Hon. GREG DONNELLY: That is what we are trying to find out—the real number. The question was about the number. Let us call it several hundred. Does the fact that there are several hundred create issues of competition or friction or tension? Is there a view that there are too many and that there should be some efforts to try to slow it down to the extent there is any growth of new NGOs? I would just like to hear your general comments about the whole issue of numbers.

Ms STUBBS: There is a lot of need that is still not met. So I must say that competition has not, from my perspective, been an enormous issue. There has been more than enough work to go around for everybody at this stage. It does not mean that there will not be and—once again, this is my view—the issue is not so much about numbers, it is about quality and service provision, and there are good arguments for small NGOs that provide a particular service in a particular area and there are good arguments for large ones that do other things. As I said before, I think it is more about cooperation and perhaps larger NGOs assisting some of the smaller ones is a great way to go—one way we are very keen to work with.

Ms FISHER: So long as there is a range of services available to meet diverse client needs. That is the important thing. Whether that takes 900 organisations or 400, so long as there is diversity.

The Hon. GREG DONNELLY: So what is your considered view across all these NGOs that are out there about the level of working together, sharing information, coordination by the Government? Are there any holes out there that you see that are not being catered for that perhaps should be catered for?

Ms STUBBS: I think I said before there is no benchmarking across the industry, and that would be useful.

The Hon. GREG DONNELLY: That is a big issue.

Ms STUBBS: It would be useful I think certainly for the public to judge how money is being spent, and certainly smaller NGOs. I think NDS does a great job in bringing organisations together and providing as much information as it can. But for smaller NGOs there is often a constraint in gathering information. It is hard enough for us and we are reasonably large but for small NGOs to have the resources to gather information would be hard. Some industry benchmarking I think would be extremely useful.

The Hon. GREG DONNELLY: Can I move on to the issue, which I think was raised in your submission, about people with low and moderate support needs? I think you said in your submission that there is a degree of overlooking of such people. The argument goes that we tend to focus on those people with high needs and high dependency rather than those with low and moderate support needs. Would you like to elaborate on that point?

Ms FORSYTH: I think it comes back to the issue of unmet need and there being a finite amount of resources available to meet the needs of people with a disability and those people that have high needs will be prioritised in a system that does not have enough resources to meet everyone's needs. We see the benefit of early intervention and of addressing needs at a lower level to decrease the likelihood of the escalation of costs as needs potentially grow. The other thing that I would say is that we would hope that something like a national disability insurance scheme would work to set a standard baseline of services available to everyone, then that can be built on in terms of levels of need and graduated as people's needs change.

Ms STUBBS: It is such a waste. Someone who has got low or moderate needs who can be helped fairly quickly and efficiently early on—

The Hon. GREG DONNELLY: Would you like to use an example?

Ms FISHER: I can think of an example back when I was a social worker more on the frontline or some of the workers that I managed: working with people with a primary physical disability who might be considered as having moderate support needs; they might, like with cerebral palsy, use a wheelchair and need a certain level of personal care support and want to move from the family home into supported accommodation. We would try to make referrals thinking about accommodation available. First of all you had the option of the Department of Housing, but that probably is too independent and they need a bit more support, so you might think "I will refer them to the ADHC vacancy management committee". But our experience has been that unless you are homeless you pretty much will not get accommodation because of the limited resources available. You know in making that referral that unless you are homeless you are not going to be able to access accommodation. So then they are often left without that option and need to remain at home.

Ms STUBBS: What about spina bifida clients? Spina bifida clients quite often may well be classed as low need and yet they may need a little bit of help in organisation, in working out what their life plan should be, getting some casework help. They do not get that and that may then lead to a spiral where they do not get that, so things go bad, they get worse, they may then end up with health problems, they may end up in hospital, which is a much more expensive drain on the system than if they had been helped earlier on. We see that a bit with spina bifida clients particularly.

The Hon. GREG DONNELLY: Is this grading of people as low, medium or high done in a formal sense or is it just informal in terms of where a person sits on a scale?

Ms FORSYTH: There are formal diagnoses of disability in relation to severity, but there is often also an interpretation based on what you need assistance in and how much of that you need that sets you in high, medium or low.

The Hon. GREG DONNELLY: Can I now go on to an issue that has also been raised by other witnesses about a need for a whole-of-government approach in terms of dealing with disability and how that might be brought about? I will read the question because it picks up a number of points you might like to elaborate on. In your submission you discuss the whole issue. People with a disability access a variety of government-funded provider services including accessible accommodation, personal care and support, respite, aids and appliances, education, training and transport services—so it covers a whole range of areas. This whole issue of trying to develop a whole-of-government approach, have you given particular thought to how that is brought about? Obviously it would be done over time in a progressive way; it could not be done quickly. Secondly, are there any models overseas that you might be familiar with in jurisdictions that perhaps arguably do it better than we do in New South Wales from a whole-of-government point of view—perhaps even within Australia?

Ms STUBBS: That is a very difficult question. A whole-of-government approach is difficult in anything and you are talking about very complex relationships. The only—and this is probably harking back—models overseas that seem to work quite well, are the disability insurance scheme models where you are working from the client out, if you like, and therefore the client has the ability to work at a whole-of-life or a whole-of-needs approach and have access to services as they need to.

The Hon. TREVOR KHAN: But that is a terribly radical approach to take.

Ms STUBBS: It is extremely radical but it works. If you are looking at something from New South Wales specifically at the moment, the example we have given in our paper—and we work with Health, we work with Education and we work with Housing and with ADHC, so we work with them all—the example of our spina bifida resource team is not a bad one because it is a whole-of-State approach, if you like, and it is looking at the transition points, which are usually the points where things go wrong, and having a single point of contact where those things can be sorted out on a case management basis. I think a lot more thinking around specialist services at the right transition points would probably assist in some way before we get to the nirvana of a national disability insurance scheme, which is where we would all like to be.

The Hon. HELEN WESTWOOD: If I could go back to the issue of workforce capacity, which we have been hearing a bit about. You talked about Northcott's decision to have an enterprise agreement rather than pay under the SACS Award. Could you give me a little bit of history to that decision?

Ms STUBBS: It was before I got there, but I can try. My understanding was that for the types of services that we provide, because we work pretty much in the community and not in centres so much it made sense to develop our own enterprise agreement. I think we are in our third iteration now. We just signed off one just recently. Clearly, the pay rates are not that different from the SACS Award—a bit higher for the disability support workers, but we have probably more allied health professionals or therapists than the majority of disability service providers. We will be much more like, say, the Spastic Centre in the type of people we employ. We have a different type of need and we need people who are able to be probably fairly independent in the way they think, fairly mobile, self-motivated. So for us to have our own collective agreement made sense, and we have used it quite effectively I think.

The Hon. HELEN WESTWOOD: You talked about your retention rate improving—is it since the EEA?

Ms STUBBS: In the last couple of years we have put a number of strategies in place and they were particularly around career paths for allied health professionals; better paid maternity leave, because we have a 75 per cent female workforce; greater flexibility, so we have very flexible work practices; and our turnover rate was around 34 per cent and it is now down to under 22, and that is in about 12 to 18 months.

The Hon. HELEN WESTWOOD: What about your disability support workers? Is there a high turnover with those workers?

Ms STUBBS: That is the total turnover rate.

The Hon. HELEN WESTWOOD: Have you noticed any difference?

Ms STUBBS: Our turnover rate was higher in allied health people than it was in disability support workers, surprisingly. We also invest in a fair bit of training for all of our employees. We just did an employee opinion survey—we did a second one—and training is one of the things that people like.

Ms FISHER: Some of our support workers are university-trained or in the process of being trained to be professionals, so we try and engage them early and provide opportunities so that they might choose to stay with us as occupational therapists for example.

The Hon. TREVOR KHAN: Have any of you had experience in the public service, whether it be DOCS or ADHC?

Ms STUBBS: I have worked in Sydney Water.

Ms FORSYTH: I have worked for DOCS.

The Hon. TREVOR KHAN: In terms of a work environment how do they compare, Northcott and, say, DOCS?

Ms FORSYTH: They are not comparable because they are completely different organisations.

The Hon. TREVOR KHAN: Better? Worse?

Ms FORSYTH: They are completely different—completely different roles, different locations. It is not something that I could compare.

The Hon. HELEN WESTWOOD: I am not sure how much you heard of our previous witness Ms Qian.

Ms STUBBS: A little bit.

The Hon. HELEN WESTWOOD: I was wondering whether or not providing services to the CALD disability population and their population is an area where you have found difficulties. I know in your submission you talked about regional and we have had a lot of information about indigenous communities but it has only been MDAA that have raised the issue of CALD communities. I was wondering if you could give us some evidence on that?

Ms FISHER: I do not remember the year but it might have been around 2004, it was quite a while ago now, we worked quite closely with MDAA on our cultural diversity plan. We offered to put our hand up and say we would really like to have an audit done of our organisation and assess where we were at and develop some strategies to improve. So we were one of the first organisations that they worked with to develop a cultural plan and they seem to—Diana was just saying as she was walking out—hold us in high esteem in regard to being proactive in strategies to be culturally appropriate with our clients but, having said that, we still have a long way to go. We are well aware of the need to provide diverse services and trying to meet the needs of our clients and we have put in a lot of strategies but, at the same time, it is something that we are well aware needs improving and I guess ADHC, similar to what Diana said, could also improve in many ways as well.

Ms STUBBS: The big issue is I think getting the message out once again. That really has to be done with CALD communities on a very low-class basis in many ways and working through the right peak bodies. One of our very successful programs that we run at the moment is an indigenous playgroup in south-western Sydney. We have also recently begun running an Arabic playgroup in south-western Sydney, and with the numbers—I was only hearing the other day—we are now probably going to open a second one because the numbers of families have increased exponentially. That is by working in the community, with the community and by word-of-mouth—that is how it grows. You have to have those sorts of strategies and that means time and energy put into making that happen, and having the right people on the ground doing it.

Ms FISHER: It is also about engaging diverse staff. I have been at Northcott for about 15 years so I can comment that the diversity has grown considerably over recent years.

The Hon. HELEN WESTWOOD: The other issue that Miss Qian raised with us was attitudes within CALD communities. Have you observed differences within specific CALD communities about disability stigma acceptance?

Ms FISHER: It is hard to generalise but certainly anecdotally I have witnessed certain families where, like a Vietnamese family may have chosen to keep the disability a bit of a secret for their child, or be a bit hesitant to request a service and so you had to work extra hard on removing that taboo. But, yes, I certainly would not comment as an expert but anecdotally I have seen that happen.

Ms FORSYTH: It is also then about individual cultural understanding of what the services are. So respite, for example, has guidelines around it being a break for the carer. Traditionally that is about the carer actually separated from the person they are caring for in order to give them a break. For some communities and cultures that is not having a break and actually separating them from that person is not a helpful way. That has come up at meetings I have been a part of around respite issues and particularly working with Aboriginal families and what respite means in the context of their individual family and cultural situation.

Ms FISHER: Even talking about translating materials. We got told that respite is not a word that can be translated, so that was quite interesting.

Ms STUBBS: So flexibility is really a big thing in working with multicultural communities because you have to fit the strategies to fit the community rather than trying to make them fit with us.

CHAIR: We heard in our first hearing that taking a person with a disability away from their place of abode is a rights issue. That is another issue that has to be addressed for respite.

Ms STUBBS: Some communities are much more diverse in terms of thinking about people with disabilities as well. It is not always a negative: It is quite often a positive.

Ms FISHER: I think the key is the flexibility that is needed for the service provision. One of the things I would say that would be ideal for ADHC is for them to enable that flexibility, whether that be around the reporting mechanisms that are required, the paperwork that is required, and things like that could be culturally appropriate.

The Hon. HELEN WESTWOOD: The Committee has been told a number of times—and you referred to as well earlier—about the amount of data that is input to ADHC and what becomes of that data. We have heard from others that they felt the amount of data that was returned to ADHC from funded organisations should be able to give them a better picture, for example, of unmet need than ADHC claims it can measure. Do you have a view on that?

Ms STUBBS: In most cases we do not give them unmet need—that is not the data we are asked for. We certainly give a lot of accountability data and service provision data. I do not know how that would necessarily help them with unmet need because that is about completion of services or progress.

The Hon. HELEN WESTWOOD: So there is not data for request of service and provision of service?

Ms STUBBS: Except that we have been engaged in the past couple of years on a therapy task force with ADHC and the Spastic Centre, which was around waiting lists for therapy services. We have collected some data from our organisations and that has been very useful. It has in fact been used to determine some funding, and some extra funding where there was need for therapy services in south-western Sydney. So that has been a very good experience.

Ms FORSYTH: And the other example I gave earlier about the local respite coordination groups. Part of that function was to try to get information about unmet need because it is not information that we pass on as daily business.

The Hon. GREG DONNELLY: The issue of unmet need has been raised without surprise by virtually all witnesses. The metric or indices used to try and get a head around it is the issue of waiting lists. It was put by one witness earlier today that that is the way in which they think the issue of unmet need can be best appreciated. Do you have a view about trying to develop a sense of what is the amount of unmet need perhaps more accurate than otherwise we understand it to be?

Ms STUBBS: That is why I think the therapy task force waiting list project was useful. It was testing a couple of hypotheses and that was around unmet need—people on waiting lists. Given there are only a few disability service providers that provide therapy services it was a useful way to do it. The hypothesis I think was that there would be duplication of waiting lists. In fact as it turned out there weren't.

The Hon. GREG DONNELLY: There were not—really?

Ms STUBBS: Yes. Each of the service providers had quite discrete waiting lists and then ADHC was able to say: Clearly there is some need that is not being addressed because we now have this evidence. I think if you are going to do that sort of thing you need to think very carefully about what you are collecting and how you are going to do it and have a properly designed project. I would not just be asking all the service providers to send in their waiting lists.

The Hon. GREG DONNELLY: And add it up.

Ms STUBBS: No, because it is clearly not good research. But I think there could be good ways to collect some of that information and there are plenty of university and research organisations around that would be well equipped to undertake some of that sort of work.

The Hon. GREG DONNELLY: Would you be bold enough to say that anything we do in this area would be better than where we are at the moment in terms of understanding this unmet need?

Ms STUBBS: I think so, yes.

Ms FORSYTH: I think it happens locally and service specifically so obviously there have been some initiatives in therapy. Anita made reference earlier to the intensive family support panel. So when there are allocation panels of bringing together services you can then look at those people that are jointly sitting and waiting for that service.

Ms STUBBS: But there is no point asking people to sit on a waiting list if you are never going to give them a service—that would be very unfair.

Ms FORSYTH: Especially if it is an intensive family support service a few months in it is not relevant.

Dr JOHN KAYE: If you had three changes you could make to ADHC, what would they be?

Ms STUBBS: To ADHC itself?
Dr JOHN KAYE: Yes.

Ms STUBBS: I would like them to measure outcomes. I would like them to clearly think about outcome measurement. I would like them to build on some of the innovative things that have been done with allocation panels, like respite panels and those sorts of things, and work closely in cooperation with providers on those, because I think those experiments have worked well. The third thing for me—and I am hogging the time because these two may have some other things to say—is I would like them to do a few more of the innovative things they have started to do on some of their newer programs. There are some great examples like the leaving care mentoring program and the early diagnosis program when people do not have to have an established diagnosis of their children before they can access the program. So some of those sorts of things I think would be great.

Dr JOHN KAYE: Anita or Liz, do you feel like adding to that list?

Ms FORSYTH: I would add that ADHC's eligibility criteria for direct services are expanded to people with all disability types. So currently people with a physical disability without an intellectual disability cannot access ADHC case management or ADHC therapy. They can be referred to the non-government sector for those services but they cannot actually access ADHC direct care and directly provided services.

Ms FISHER: That is what I would have added.

The Hon. GREG DONNELLY: Why is that? Is that the policy?

Ms FORSYTH: The criterion for accessing services is intellectual disability.

CHAIR: Thank you for your evidence, which has been very helpful to the Committee. Some questions may be sent to you for answer over the next few days.

(The witnesses withdrew)

(The Committee adjourned at 4.40 p.m.)