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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY CARE AND SUPPORT

MS P. SCOTT, Presiding Commissioner
MR D. KALISCH, Commissioner

TRANSCRIPT OF PROCEEDINGS

AT CANBERRA ON TUESDAY, 13 JULY 2010, AT 9.32 AM

Continued from 12/7/10

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MS SCOTT: Good morning. Welcome to the public hearings for the Productivity Commission inquiry into disability care and support. I thank you for attending today. My name is Patricia Scott and with me, David Kalisch. The inquiry started in April, with a reference from the treasurer. The Australian government has asked the Productivity Commission to examine the feasibility, costs and benefits of a national disability scheme that will provide long-term essential care and support, manage the costs of long-term care, replace the existing funding arrangements for those people covered by the scheme, take account of the desired and potential outcomes of each person over a lifetime, with a focus on early intervention; provide a range of coordinated support options, including accommodation, aids and appliances, respite, transport, day programs and community participation, assist people with disabilities to make decisions about their support, provide for people to participate in education, training and employment where possible.

The Australian government has asked the commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. We have already taken a range of submissions from organisations and individuals with an interest in the issues and an issues paper was released in May.

We are grateful for the submissions already received and submissions can be downloaded from our web site at www.pc.gov.au. While we would like to get submissions as early as possible, in view of concerns raised by some participants, the commission has extended the due date for initial submissions to Monday, 16 August 2010. The commission also welcomes second, third and fourth submissions. Feel free to put in as many as you wish. These submissions may include additional points you wish to make, comments on other submissions and results of community consultations. The purpose of these hearings is to provide an opportunity for interested parties to discuss these submissions and their views on the public record. It is also an opportunity for the commissioners to the ask questions to those presenting materials.

Further hearings will be held in Brisbane, Perth, Sydney, and we've already completed hearings in Hobart, Melbourne and Adelaide. We will then be working towards completing a draft report in February next year for public comment and we will then invite participation in another round of hearings after interested parties have had time to read and consider our report.

We would like to conduct all our hearings in a reasonably informal manner but I do remind participants that a full transcript is being taken. For this reason, comments from the floor cannot be taken, but I will provide an opportunity for those who wish to make a brief presentation or comment at around 11 o'clock. I have to say we have had responses to most of our invitations for people to come forward if they wish to at the end of the scheduled evidence taking to also have comments made by anyone from the audience if they wish to. Participants are welcome to comment on the issues raised in other submissions or provided by way of evidence by other submitters.

Transcripts will be made available from the commission's web site following the hearings. This is a good time for you, if you haven't already done so, to turn off your mobile or switch it to silent because we wouldn't want you to interrupt someone else's evidence by having a phone buzzing.

Safety: to comply with the requirements of the Commonwealth occupational health and safety legislation, you are advised that in the unlikely event of an emergency requiring evacuation of this building to please follow the instructions of the PC staff. If you require assistance, please approach one of our staff.   I now welcome to the table Carers Australia. Good morning.   We've set aside about 30 minutes for your time and just for the record, would you just like to state your name, your organisation and would you like to make an opening statement and then we might ask some questions.

MS AIESI (CA):   I'm Sue Aiesi, Carers Australia.

MS BESWICK (CA):   Jess Beswick, Carers Australia.

MS RICHARDS: And Sally Richards, a carer.

MS AIESI (CA):   Our opening statement, because we represent carers, is more about ensuring that throughout this process, the needs of family carers are considered. Carers play a very strong role in the lives of people with disability. Often they are the advocate, the decision-maker, the doctor, the nurse, the chef. Their role spans across all aspects of the person's life. Carers also have needs of their own. Often because of the intense caring role, they become exhausted, they can become injured themselves and have disabilities themselves in the long term. So we're asking the commission, in considering a long-term care and support scheme, to fully understand the role of family carer, the unpaid family carer, in the lives of people with a disability, and looking to address carers' needs as well as the person with the disability. There's linkages between both and supporting the person with the disability no doubt will help the carer.

However, the carer does have needs of their own if there's an expectation that they're going to be able to continue to care. I think we all know the amount of care that's provided by family carers, 1.2 billion hours of care in 2005. 79 per cent of the assistance required by Australians due to disability or illness is provided by family carers. So carers provide the majority of care to the majority of people needing care.

The other thing to understand I guess is carers do provide the care in a very individualised way. They have a very close relationship often to the person that they're providing care to and through this, family structures and relationships are preserved, so they're a very, very important part of Australian society and what they do is - how best to describe it - it supports the people who need the most support. So we're asking that their needs be considered.

We've undertaken a number of consultations just recently and spoken with a number of carers and there are a few themes that are coming across. One is there's confusion around "profound/severe". The people we have spoken to whose child might have autism or they may have two children with autism, for example, they think that this system will be for them. These children may not be in the profound or severe classification but there is an expectation that they will be assisted through a scheme such as this.

The other messages that are coming through I guess is the cost of care, and Sally will have talked about the cost of care - Sally will later talk about the cost of care - but how do we best address the additional costs associated with caring for a person with a disability. That's very important for family carers and for families. How do we best cover the additional costs? We have - and apart from what Sally has - one carer I know in Queensland who has borrowed $70,000 from her parents. She has a son who is now 12. He has a range of disabilities. For example, he needs a special wheelchair. The wheelchair that he needs is not available through a government-funded program, so it costs an awful lot of money. If she wants her child to go on camp, for example, with the rest of the schoolchildren, she has to pay for a nurse to go away for the two days, so that comes out of her pocket. Sometimes some of the costs that she has are reimbursible, but she actually has to pay for them up-front and then be reimbursed, and this is a struggle for a single mum. So that's a very strong message that we're getting.

The other messages are the majority of people are talking about a Medicare-type levy, just an increase to the Medicare levy. The other message that we're getting is the linkages between the disability sector and the aged sector and how is this going to cross over. For example, if you're caring for a parent with a disability and a child with a disability, often you're in two systems and it's a very complex area for families. We've had consultations with people who have younger onset dementia, for example. People with younger onset dementia often have comorbidity, so they may have Down syndrome or they may have another illness or disability. However, the expertise for dementia sits in the aged care system, even those these people could be in their 30s or 40s.

For the most part - and this is in Canberra and we've only spoken to these people in Canberra - they're happy for their needs to be under the aged care system, even though they don't fit within that age bracket. So it's quite a complex mix across the two. There's no expertise around younger onset dementia outside the aged care system at the moment.

The other message that's coming through quite clear for us is training of paid careworkers. What's happening is a lot of carers are finding that they need to train the staff that come into their house themselves. This is particularly in relation to autism or severe disabilities. This is taking a lot of time. The carers are worried that once they leave the house, if they leave the house, they're not going to get the same quality of support. We have one carer who had a $5000 package but has only spent $350 this year because she can't get qualified staff to come in. She has two children. So therefore the person who comes in can only look after one child, even though the two of them have autism, so they're only there for one child. So she's finding it incredibly difficult to get appropriate support and training and she's spending a lot of hours training people.

The other message I guess that's coming through for us is choice and control, so more around individualised funding packages but only where family carers and the person they're caring for want that, and there's a lot of instances where that's not possible, particularly with older people who are caring for their adult sons or daughters; they are happy with the status quo. So it's all about choice and flexibility in service delivery. High quality support is really important. They're the sort of main messages that are coming through, I guess.

There's one other thing: there's a need for provisions that allow carers to be able to retire and I don't mean paid retirement, I mean retire from caring, when they've been caring for 40 years, and that's a really strong message that we're getting. So accommodation, suitable accommodation is very strong. I think it's probably one of the strongest messages that we get, "What will happen when I am no longer able to do this?" so we need supported accommodation. That's what I want to say. Jess?

MS BESWICK (CA):   I think the other important thing from just an organisational point of view is Carers Australia believes very strongly in representing the views of all carers and the diversity of carers, so I think it's really important when the commission is doing its work that any sort of changes in a scheme also consider maybe the individual differences in groups, so indigenous carers, carers from non-English-speaking backgrounds, and I just think that's an essential part, and especially carers in rural and remote areas, there's very big differences there in the equity of access to services, so we would really stress that that's an important area to consider.

MS RICHARDS (CA):   I don't really have anything to say, I don't think, at the moment. I suppose what I would say is that one of the hardest things I think for the commission when they write the report is going to be to work out that whole thing about who's in and who's out. Where do you draw the line? Everybody is going to think that this is going to be for them and this is going to address some of their problems and that just won't happen. It's going to be very tricky how actually who is covered and who isn't covered is delineated and assessed.

Just going back, you must have heard of person-centred planning, and when we talk about families with two kids with autism or a single mother who's spent $70,000 on equipment, I mean, really - somebody was talking outside, you were, about somebody who's got a package and they don't want to lose what they have got - the only way to really do that is to look - and I know this is difficult - but to look at each - there will be some broad rules, but it's got to be about individual families and individual people with disabilities. What is this life like? How does this woman - and I'd say it's overwhelmingly women who do the work, not always, but it is the majority of women - get out of bed in the morning and face the sort of struggles and challenges that she has to face every day and what does this family need is the way that it has to be done - and also, I just wanted to say the portability of whatever support is available across states and territories.

MS AIESI (CA): That's very important. This particular lady in Queensland - she lives in northern New South Wales. If she has to take her son to hospital, she has to go to Brisbane but because she lives in New South Wales, she doesn't get subsidised accommodation, so she has to pay for accommodation while she's in Brisbane with her son, so it's very important.

MS BESWICK (CA): I think also the idea of assessment - it was prompted by what Sally said - I think it's important for the commission to consider maybe, if you're looking at ways of figuring out how people qualify for the scheme that you could consider not just looking at what someone perhaps with a condition or disability - their needs and requirements, but the level of care that's actually required and how you measure that more effectively as opposed to what someone generally with the condition would have, and that's about taking an individual approach as well.

MS SCOTT: Okay, thank you very much.

MR KALISCH: One of the things that we're often hearing about is the burden that's being placed on carers and for some people, they're just coming to breaking point. You gave the example of someone who has been caring for 40 years or so and ageing carers. Is there still an expectation that there will be still significant and considerable informal caring, even once a new scheme is put in place?

MS AIESI (CA): Absolutely. I mean, people care for a number of reasons. Often, and one of the main reasons, is a sense of love and commitment to the person for whom they are caring, and people do this willingly but they need support to be able to continue doing it. I think, for the most part, carers will do it, but they really need support.

MR KALISCH: I suppose following on a little bit to the individualised funding dimension, one of the major contentions that we're hearing is about whether, within that individualised funding, there could or should be the capacity to provide a payment or an income for family carers. Does the association have a particular view about that?

MS AIESI (CA): Yes. We believe that if carers are able to do the work, the caring, they just be eligible to be paid. For example, if you get in a nurse overnight, if you want to go out, it might cost either yourself or a provider four or five hundred dollars to do it because it can cost like $70 an hour. There are carers out there who consider that them being able to be paid for doing what they do is important. There are other carers who don't think it's so important. What's more important to them is the ongoing support and respite, and just to be able to do it. Once again, it's individual, and carers have different expectations.

MS SCOTT: So there's no official view of the association on that though? I just want to flesh this out a bit more because we are hearing and seeing in submissions quite different views, and maybe that represents the diversity of opinion, so you may not be able to settle on one conclusion, Sue, so it's fine to say that.

MS AIESI (CA): Yes.

MS SCOTT: Some people point to the New Zealand model as a positive and some point to it as a negative, the fact that the accident scheme over there has provided payments to family members to act as carers and some see that as equitable, and other people see it as producing averse incentives that end up creating bad outcomes down the track because sometimes the support doesn't diminish and in fact families become tied to high levels of support as the principal means of income. Does the association have a definitive view on this? I don't mind if it doesn't. It doesn't reflect badly if it does or - - -

MS AIESI (CA): We do have a definitive view on superannuation.

MS SCOTT: Right, okay.

MS AIESI (CA): We would like carers to be eligible for the 9 per cent superannuation, so when they get to retirement age, they actually do have something to retire with, so that's a very strong view that we argue for constantly. As to actually paying, we don't have a definitive view on that as yet. The views are very different but certainly superannuation is very strong for us, that carers should have access to superannuation.

MS SCOTT: 9 per cent of a salary - - -

MS AIESI (CA): 9 per cent of average weekly earnings.

MS SCOTT: Okay.

MR KALISCH: Just on that dimension a little bit more, does the association have a view about the adequacy of carer payment, carer allowance? While that's not within our remit, it obviously - and some of the conditions that go with that in terms of participation requirements - - -

MS AIESI (CA): There's no participation requirements with carer payment or carer allowance. Carer payment of course is means tested, assets tested; carer allowance is not. Carer Payment (child) was reviewed, as you would probably know, to make it easier for people to access. We have a number of concerns around Carer Payment (adult) and the transition from when you turn 16 through to an adult. That's quite a difficult process and quite a time-consuming process. We work very closely with Centrelink to try and ease that burden, but Centrelink is the deliverer, not the policy organisation. We would like to see a review of Carer Payment (adult) to make that fall in line with Carer Payment (child). Is it adequate? No. The reason I say no is because of the cost of care. If we look at, for example, things like the additional washing, it's water, it's power, it's whitegoods, washing powder, all those sorts of things, that's just one part of it. There's special food. There's a range of equipment. So the cost of care has a major impact on families. So is carer payment and carer allowance adequate? It's not, if the costs of care are not addressed.

MR KALISCH: So that might provide an avenue if this scheme was to encompass and cover some of those costs?

MS AIESI (CA): Yes.

MR KALISCH: You talked about recognising the needs of carers. Can you just elaborate a little bit more about that.

MS AIESI (CA): Carers' needs are diverse, I suppose, and each carer is an individual in their own right. We believe carers need education and training and they need access to appropriate education and training right throughout the caring role. It could be at the beginning of a diagnosis, the birth of a child, it can be throughout when conditions change, but that's a really important part for carers. It's more than just supporting carers to do that. We believe strongly there's savings associated to the government with having carers trained properly. For example, even something like manual lifting, if carers hurt themselves, the person they are caring for is likely to end up in hospital, the carer could end up in hospital, so there's a double-whammy. So that's a very, very important thing for carers.

Other support is respite, access to appropriate respite when they need it. That's very difficult. Counselling is another strong need for carers. They're sort of the main things that we talk about. Workforce participation is another area that carers would like to see more movement in, I suppose, flexibile working arrangements. Sally can back this up; there's now the right to request flexible working arrangements if you have a child with a disability under 16. That doesn't exist once the child turns 16. What happens is that's often the most crucial time in a family's life. The child leaves school. One of the parents often needs to give up work to care for that child, where they've been able to work even part-time up until then. So that's a very important issue for carers: how can they continue to be socially included through work and other ranges of things when there's not a great deal of support after the child turns 16.

MS SCOTT: Thank you. I'm conscious of the time but I think we might go five minutes into our break time, just to make sure that we've got enough material from you on some of the topics you've suggested. For example, Sally, one of the reasons why you're back here today is to talk about cost of care, and I wouldn't mind if there's some examples that you could give. Sue has already given the example of the greater load in terms of washing, but if you give some examples from your experience or cases you know, that would be quite illustrative.

MS RICHARDS (CA): I've got one example just from my own life. Last year and this year, I went away for two weeks. As you know, my son Jason is employed and he's actually fully supported which is paid for through his employment and my 10 hours of allocated support from 8.30 until 4 or 4.30 every weekday. So my sister Lisa comes. I have got a small individual support package. My sister comes from Texas with her husband. She becomes an employee of a non-government organisation. She lives in my house and she does my job, so she does the mornings, the evenings, the night-times, which includes a lot of awake hours which she gets paid for, and weekends, and for two weeks, her gross income was very close to $6000. So that's what it costs to cover what I do - that'd be good, wouldn't it, if I could earn $3000 a week, that would be fantastic - but anyway, that's the real cost of the care that Jackson needs outside of all of the other care that he already gets.

Can I just say one very short thing about employment. I've had a lot to do with many families and there's not a mother that I don't know who would prefer to go to work than to stay at home, because they say to me, "I love going to work, work is my respite," which is what I always used to say. "I'm going to work, whoopee, have a break." When you stay at home for 24 hours with the person with the disability, it's incredibly isolating and isolated and families become more and more and more isolated. This business of the thing that cuts out when they're 16, they actually in many cases need - you know, they're bigger and heavier. They need more work and more support but you don't get it. So whether you pay somebody to stay at home or not, I think there's a lot of things to consider about that. Wouldn't it be better to provide the support for the person who's doing the caring to go out and get some social interaction, earn an income, use their brain, have a bit of a life? That's what I'd say about that.

MS SCOTT: Okay. I just want to check I've got it right: when your sister comes from the US, she effectively is engaged by a nonprofit body so that she can actually take your role and for two weeks the cost of that is at least $6000, because there's probably other on-costs as well.

MS RICHARDS (CA): Yes.

MS SCOTT: Your perspective is that while people want support, that support doesn't have to be a payment to the mothers or the fathers; what they really want is all the other supports, the respite, accommodation, counselling, the capacity to go and work when they would like to work to keep them engaged and happy and healthy so that they can actually continue providing the informal care.

MS RICHARDS (CA): Yes.

MS SCOTT: Is that a reasonable summary?

MS RICHARDS (CA): That's a good summary. It's just what Sue said, it's about the choice. Give people the choice.

MS SCOTT: Sue, you gave an example of the mother - I think it was a mother - who has a $5000 package but has only spent a small proportion of it because she's concerned about the untrained staff. We've heard a variety of views about this and David is particularly interested in workforce issues, so I wouldn't mind exploring a few things with you and just see what your opinions are. One is that the attendant care workforce needs to be trained and qualified, and certificate IIIs and IVs or even something more should be required. That's one view. The other view is that really it's the aptitude and the attitude of the person coming into your home, looking after the one you love, that's actually more important.

The New South Wales lifetime care model, I've seen their forms, actually looks at the need and then works out the level of attendant care required. So for some people it might be a certificate III or it might even be a neighbour, but for other people it has to be a nurse and so on. Could you comment on which model, I guess of those three, the one that has formal qualifications as the hurdle, another one who says, "No, qualifications mean nothing because it's the attitude of the person," and then one that might be about trying to almost rate the type of care required. Would you comment on that?

MS AIESI (CA): It's a bit of all of those. I'm actually on the disability workforce strategy reference group that's looking at the disability workforce over the next 15 years. One of the things that has come out, I suppose, is first of all, quality staff within the disability workforce, if you like, and then it's trying to develop a career path. Skills are absolutely essential. But then it might be looking at specialist skills, so somebody within that workforce might learn skills around dealing with somebody with autism or dealing with somebody with severe disabilities. Attitude is absolutely critical. Some of the feedback we get, they get people coming into their house and they're not treated with respect or dignity, so that's absolutely crucial. So it's a balance, it's trying to find that balance.

I think one of the most important things when you look at a disability workforce, it's trying to make a career out of it and how do you best do that, so it's changing the notion that if you work with disability, there's no career path. So what the workforce reference group is looking at is how do we actually develop this career path and I think that's really essential. It's giving people who do work in the disability sector acknowledgment, recognition and a career path. I think over a period of time, if we can achieve that, things will start to change. But certainly if you asked a lot of family carers, attitude is really important, but skills for others is too.

MS SCOTT: Sally, would you like to comment?

MS RICHARDS (CA): I never ask anybody I employ if they have got any training in disability because it doesn't matter to me. I'm one of the people who talk to the person; it's their attitude. Do they speak to my son? Do they acknowledge he exists? Do they have the right sense of social justice? That comes first. I can teach them how to work with Jackson. I can do that, and everybody - this whole individual thing, you know, it doesn't matter if you get somebody with 15 certificates in disability, you still have to teach them about your person, because they all have their idiosyncrasies. Now, I think medical conditions are a separate matter. I think you probably absolutely definitely need training in certain medical conditions, but for Jackson, attitude first, I teach them the stuff they need to know. I've had some fabulous workers - so that's me; it's a vexed issue, I think.

MS AIESI (CA): Just on that, the other thing that's coming out is the people who come to the house, it changes quite regularly and often carers, because of how the package is funded, they are actually not supposed to have direct contact with the person coming into their house. So if this lady with autism needed respite and wanted somebody to come into her house, she can't speak to the person who's going to come in directly, she has to ring her case manager, who then gets in touch with the service provider, who then gets in touch with the paid careworker to see if the paid careworker is available on the day that she needs it. So what some people do, which is just a little bit sneaky, they get the mobile phone and they check them out themselves first and then they go through this whole process and it all works out. So that's quite complex.

MS SCOTT: Could you document that? That would be quite useful.

MS AIESI (CA): Yes.

MR KALISCH: I suppose I'm just interested in the workforce thing. Is there a sense that there will be a sufficient workforce for the people or are people fairly pessimistic about it?

MS AIESI (CA): I think there is a little bit of pessimism, but certainly they're working very hard at the workforce reference group to see how they can, over the next 15 years, build up a sustainable workforce.

MS SCOTT: Sally, if you didn't have your sister, would you be able to get that two weeks off a year?

MS RICHARDS (CA): Maybe, but Jackson, he'd probably have to spend one week at one respite house and then another week at a separate respite house. What's brilliant about that is that Jackson stays in his own home and has his routine and goes to work and nothing changes except the person who's there who's a younger version of me, not as good looking though. But can I just say, somebody said to me once if you employ a person for a position rather than an organisation - because you hear this all the time, you can't keep staff - and I thought that was interesting. You would recruit somebody for a specific position with a specific person which is what I've done with Jackson and JACKmail. Now, I've had my current support worker who works with Jackson for 24 hours a week for two and a half years and he's not going anywhere because he feels totally valued, respected. He likes his job. My job is to support the support worker, so what I do is support Phillipe so that he feels all of those things and I pay him really well for a support worker - well, I don't pay him really well. I think a career path is vital and there's this whole thing that the staff who do the support work need to feel valued and that's got to be reflected in the money they earn, their conditions, the path that they might have. I think it's possible to get a strong workforce but we've got to change things.

MS SCOTT: Thank you very much for your time.

MS AIESI (CA): Thank you.

MS BESWICK (CA): Thank you.

MS SCOTT: We're waiting on one person who has been detained - has just arrived. That's great. I welcome then UnitingCare who can come forward, please. Thank you for coming along today. For the record, could you identify yourself and your organisation and then if you're comfortable, to make an opening statement. We've set aside 30 minutes. At this stage, is there anyone in the audience that would like to take the opportunity of making some impromptu comments after we've have heard from UnitingCare? Is there anyone who would like to take up that opportunity? No, okay. You have 30 minutes, thank you.

MS HELYAR (UCA): Thanks. I'm Susan Helyar, the national director of UnitingCare Australia.

MS INGLIS (UCA): I'm Alison Inglis, a program adviser with UnitingCare Australia.

MS HELD (UCA): I'm Rhonda Held and I'm doing some contract work for UnitingCare Australia.

MR PINI (UCA): I'm John Pini, I'm the director of disability services for Lifeline Community Care which is an agency of UnitingCare Australia.

MS HELYAR (UCA): So today we wanted to come and talk to you as we're finalising our submission. We know that there's an enormous amount of interest and input into this process, so we were hoping to get a bit of a sense from you around whether we can best value add to that exercise, rather than just providing you with pages and pages of information that you might already have. The UnitingCare network, we like to say that we're twice the size of McDonald's and we employ more people than the coal industry, so that means we have 1300 sites across Australia and 35,000 staff, supported by 24,000 volunteers, so we work across the life span from early childhood - some antenatal care, but early childhood - and then up through to aged care. We also work across the kind of issues of vulnerability that are in the community, so around disability, mental health, housing, families living with disadvantage and financial hardship, employment support and then all the issues around ageing and the impacts of ageing on the living and participation in the community.

So it's from that perspective that we are looking at disability issues. There are some specialised disability support services which John runs and Rhonda has run for UnitingCare in the past in Victoria, but also people with disabilities access that broad sweep of UnitingCare services. We're very supportive of the concept of an NDIS, for the reason that there's a need for greater certainty for people with disabilities so that they can actually plan their lives and a funding mechanism that enables that would be highly valued by people and their families. From a service provider perspective, that's also critical because it allows services to build a long-term engagement with people with some certainty around what capacity they will have to offer and where there can be value-add from the service or from other sources, but what will be some kind of baseline financial support that will be available to people.

But there's a real issue here around - and I know that the commission has heard this from other people - but a fundamental mechanism isn't a solution in itself. There's a real concern that the service system isn't set up in a way that really enables choice and wellbeing and a full life for people with disabilities. So even with a funding mechanism in place that enables some more certainty, there really does need to be fundamental change in the service system, both in the disability service system but also in the wider service systems so that the interests and expectations and aspirations of people with disabilities are well understood and attended to in non-disability specific services.

The other issue I think we're trying to grapple with is what is the role of government in the context of if an NDIS is put into place, what is the role of government? Is it just a residual role or is there still a foundational role for government to be resourcing service infrastructure, including both the physical and also the workforce and the service options? We'll try to present some information on what we think would be an important role for government. I guess we would be very keen to see that the role of government isn't then reduced to a residual role, that the government continues to maintain a responsibility to people with disabilities as citizens, in the same way that they have a responsibility to other people with needs. But how that actually pans out in practice is a bit complex and tricky.

MS SCOTT: All right. You said that you're grappling with the issues and you're right to think that we're grappling with the issues as well, and one goes to eligibility. We are now starting to hear a variety of views about whether people with mental illness should be part of the scheme. Now, in the issues paper we tried to distinguish between a temporary condition versus people who require long-term assistance, possibly because of an episodic nature. Now, given we've got people who have had very practical experience in service delivery, what's your attitude about who should be in the scheme and whether that should extend to people with mental illness?

MS HELYAR (UCA): I might just make a couple of comments but I think John and Rhonda are well placed to speak about this as well. Our view is that people with mental illness have a long-term condition. For a number of mental illnesses, it is a lifetime condition once it's present and that whilst there's a clinical response that's needed that would be outside of the scope of potentially an NDIS, there's functional barriers for people and they are very similar to people who have either lifelong acquired disabilities or a disability that they're born with. So I think on that basis, our sense is that we should be looking at what's the life experience of people and do they have like barriers or challenges that they face, rather than what's necessarily the cause of that, and are they alike in terms of what you can expect in terms of the long term and what that would mean in terms of long-term certainty and planning to enable them to participate fully in the community.

MS SCOTT: Okay, thank you.

MR PINI (UCA): UnitingCare is a big agency, as you've heard, and hold a diversity of views, so I might present one that I've got from my experience. I would try and have a scheme as broad as possible, so I'd be saying, yes, mental health should be in, but you then may have some layers and grades within that. I think one of the confronting things for me was when I talk to some of my colleagues in Queensland and we talk about people with intellectual disability, they are able to demonstrate that a very significant number of them have a mental health issue as well. A significant number have depression because of the really crap life that they've had to experience. Now, that seems a reasonable response to their very ordinary life, so I'd be saying mental health should definitely be in.

MS HELD (UCA): I would add to that and just say that the last thing we would want is for people with dual disabilities like that to be catered for with their physical or intellectual disability in one scheme and then have to go elsewhere for their mental health support for their functioning and daily living, so as much as that can be embraced in the one scheme, that would be very beneficial to the individuals.

MR PINI (UCA): For me, some of the stories are the things that are important. I ran a service in Rockhampton for the government and there was a person who had a dual diagnosis for 20-something years and when we attempted to get her mental health services, the clinician who controlled access to those found that she was cured and that she no longer had a mental health condition and therefore didn't have to deal with them. So the boundary issues are really critical for people getting a reasonable life and a decent response from people who are supposed to be providing the response.

MS SCOTT: Just as our previous witnesses - you might not have caught their testimony - but someone with Down syndrome with early dementia, they might find themselves in a medical model and away from a social disability model because that's where the expertise is. It has been put to us - and I'm just testing these propositions, I haven't formed a view - that in mental health, often it's a medical model and just as you said, people want to divide the person into one system or another, rather than thinking that there's comorbidities. We could get to build a new system, but you don't think the predominance of the medical model would sway you to a different view on the mental health issue?

MR PINI (UCA): Again my experience is that there is a history across states of pushing people across the boundary, "It's your problem and not mine." If you then sort of reconceptualise things and say it's about providing something for this person and drawing the people from mental health, drawing the good medicos and get someone a well-rounded service, that ends up costing you less because they get a response in a timely manner.

MR KALISCH: Can I just follow it up a little bit more, John. So the issue you're seeing is that somebody with comorbidities essentially gets no service because they're too difficult to deal with, in some instances?

MR PINI (UCA): The short answer, yes, particularly if you're defined as having behavioural problems as well.

MR KALISCH: It's obviously the case that you need to draw on expertise from the health sector and from other community services as well.

MS HELYAR (UCA): That goes to the question of: how do you configure a response to someone? Is it based on the workforce view of what their skill set is or is it based on what a person's assessed needs are but then the workforce responds to that in a way that gets people to the point where they're having more participation, more wellbeing? I think the mental health sector is shifting, in terms of talking a lot more about recovery models, so there is some space in the mental health system to start to talk differently about people and what they need. I think that's what we've talked about with our network, that it's a very challenging thing about system transformation. This isn't about who the workforce is and what your skill set is, it's about who people are and what their needs are and that's the really hard shift for us to make.

MS HELD (UCA): A good individually tailored system that you'd call "independence promoting" and in mental health you would call "recovery based" basically look the same in terms of principles. If you're planning around the individual, you're trying to plan for a life in the community, that's included in the community, the disability itself is probably less relevant. It's more about the person's goals and what they want to do.

MR PINI (UCA): I think one of the things is that people with a disability look through their window and define things that way, so I was interested in the conversation you had with Carers Australia because people were talking about the need for respite, accommodation support, community access et cetera; that's all disability speak. That's not someone having a good life. That's segmenting people up into the blocks that we've chosen to call it, so we can organise the funding in a particular way.

I've got a young man in Brisbane and he was going to a day service and he used to steal things at the day service. He was perceived as having a behavioural problem there and not fitting in there. The traditional response to that is you would get the behaviour support specialist in to come and work with him. The two questions that my savvy direct support worker asked was, "What's his behaviour trying to tell us? I want to meet Warwick. I want to find out what Warwick is doing." Now, after a relatively intensive discussion, he was able to establish that Warwick wanted to actually build some things, so he was taking things to build things. The fact of it was that they were being stored in his house and his house was becoming overwhelmed with stuff. From there, he's done some work with him and Warwick now builds furniture out of recycled goods. He works with garbage trucks up there as well and does some very positive things. He has exhibited at the Ekka up there as well and he's now got a meaningful life in terms of he's got a commission to provide the furniture for a cafe. So the difference is let's not try and have all the windows on Warwick that we look through, it's what we're trying to get for him and it's about a decent life.

MS SCOTT: Given that you're such a large organisation with more sites than McDonald's and more employees than the coal industry, I wonder whether you've got a particular strength that you could employ in your submission that maybe some smaller organisations don't have, and that is because you work across jurisdictions, you know which bits work well, and in thinking about designing a new system - and you're focused on the system, as we are - that you might say, for example, regional case managers in WA, tick - I don't know if you do - the flexibility of the funding mechanism in a particular state, the lifetime approach of the New South Wales accident scheme - I don't know, you might find a particular feature in Tasmania that you think has good elements, and in some ways you could point to things that work well, are proven to work well; early intervention strategies that you think are particularly worthwhile. That would help us because then we could then take your examples and explore them further. We're doing our own work as well, but given that you've got 35,000 people on the ground and 24,000 volunteers, that's a lot of brainpower that you can access that we won't be able to. So I'd be particularly keen to get that, and if you have a view about, "It looks attractive but don't follow it," the rhetoric is nothing like the reality, that would also help us because I'd have to say that that's one of the things that staff members have encountered, sometimes the gap between the lofty words and the reality of the situation.

MS HELYAR (UCA): We'd be very pleased to do that.

MS SCOTT: Thank you.

MR KALISCH: I suppose along those lines, the other thing that I was particularly interested in was in your opening statement you talked about having worked across the life cycle and we've heard a lot of comments about difficulties at key transition points, particularly when kids leave school, and just whether there are some experiences from your service system or experiences with other policy program settings where people have dealt more effectively at some of those key transition points or whether you think there are some major improvements that need to take place.

MS HELYAR (UCA): I'll ask John and Rhonda to speak to that, but just before I do, the Senate has just finished an inquiry on the transition of disability and ageing and we've put a submission in to that, so we'll attach that to our submission because that's another key transition.

MS HELD (UCA): I think just addressing both of those points, having come from the Victorian system which has an individualised funding model, one of the key lessons we've learnt there is the need for capacity building, and Susan talked earlier about the system needs transforming and services need support with that, but in the same way, families and individuals with a disability also need capacity building to make the most of the system and so in terms of things like transitions, it's enabling parents and kids, say, at 16 to have the information about what the options are when they turn 18, so they have got a couple of years to actually plan, know what's ahead, know what the obstacles have been, to think about where they want to go. So investing in information and education for families is one key thing that has worked really well in a couple of small projects in Victoria just to build that capacity to actually make the most of the funding.

MR PINI (UCA): I think one of the best things I've seen in Queensland and from Western Australia, and it seems that every state has got its form of it, is that of local area coordination, the role of being a guide for someone through the maze of the service system, both disability and the mainstream, and try to do that, so I would encourage that as an option. I've recently written to the state minister about that, saying we really support that. But one of the clear things is you need to guard against bureaucrats feeling they need to control that. They need to steer it, not control it, because it's about local capacity building and flexibility within local communities.

It really goes to similar sorts of things in the bureaucracy as well. Government departments are made up of nice, neat little lines of however we can configure them. Brave public servants work across those until they get too brave and people find out that it doesn't neatly fit into this box. They're the people that create the space for people to get things across health, across disability and across child safety as well because I have a life across all of that and so to people with a disability.

MS SCOTT: Can I go to a different topic now, and that's block funding. We've heard a variety of views about this, the necessity of maintaining block funding in order to provide certainty and maintenance of investment and infrastructure by service providers, and the other view is that block funding is the work of the devil and it doesn't empower families and people with disabilities and it doesn't provide choice. So you have an interesting perspective as a major employer and a major service provider. What's your official view on block funding?

MS HELYAR (UCA): Our view is that the service system needs to be responsive to people who access it and the funding systems need to support that. Rhonda and John can talk about this in more detail, but there's certainly been experience in areas associated with ageing and we hear stories about what's happening with the roll-out of the specific autism funding, whereby it's all very well to have individualised funding but if there's no infrastructure through which to spend the funding, you're kind of stuffed anyway. So I think the issue is about: what's the point of the funding? The funding is to enable actions in the lives of people and I think there's probably a need for two - there's a need for base funding that enables the service infrastructure to be sustained, to be available to people, and that there's a need for much more flexibility and choice in how individuals would actually utilise what their entitlement is in a funding sense.

MR KALISCH: That's particularly tricky, I suppose to state the obvious. If you're looking for a responsive system, then the last thing you want to do is actually provide infrastructure support right across the board, particularly for those that are not providing particularly good services, where ideally you'd actually want to see them exit out the system.

MS SCOTT: Can I just explore this a bit further. When I buy my carton of milk, I provide effectively a payment hopefully sufficient enough to ensure the supply of capital into the future and also for the ongoing production and a reward for incentive and risk taking. Why couldn't that work in the disability sector?

MS HELYAR (UCA): I think Rhonda can speak on that.

MS HELD (UCA): I guess there's a couple of points here. One is it depends what sort of infrastructure you're talking about, so if you're talking about capital and buildings and those sorts of things, there's certainly an argument against investing too heavily in out-of-date models that maybe people won't want to purchase. If you take, for example, the United States model of the cash and counselling, the counselling component of that is a given, so everyone gets access to the equivalent of a financial adviser or the person who is going to give them access to the information and the support to actually make the most of their funding, so that sort of infrastructure is something that maybe people wouldn't choose to buy if they had a choice about their funding, but it's actually very, very important to help them make the most of their funding.

I think there are some lessons to be learned in a couple of areas with the mental health respite program, for example, where the Commonwealth carelink and respite centres were given brokerage funding for carers of somebody with a mental health issue and there were just no options for them to purchase, so there was nothing out there, so they had all this money and there were no activities and no services actually set up with staff that were skilled to actually respond to that need in a flexible way. So it wasn't about buildings or anything, it was just about having people who knew how to actually deliver that service.

I guess the other caution to be learnt from the child care sector is fostering a whole lot of private service provision, where you put a whole lot of money into the system, and also in Victoria with the Transport Accident Commission and seeing private providers maybe exploit that to some extent as well - you know, services being overpriced, families being let down by private child care providers et cetera, so there are some cautions in that as well.

MS SCOTT: I wouldn't mind again your submission exploring this at length. I'm very interested in your reference to families being let down by the TAC because some people have raised TAC as an exemplar for us to have a look at, so hearing an alternative view would be interesting. This goes back to one of your earlier comments about the role of the government, is it just a funder and leaves it to the market or is it a provider in other ways. Can I come back to your example, Rhonda, of the mental health thing. I wouldn't mind knowing why that didn't work. If there was instituted a scheme where providers could have some confidence that funding was going to be ongoing, it wasn't a two-year pilot or something just between two key election dates or something, you had some certainty of continuity of demand, would that make a difference or is that the reason why the thing fell over?

MS HELD (UCA): I think there were a couple of reasons. One was - you know, building on John's point earlier - it was a scheme designed in the disability mode which people in the mental health sector didn't necessarily understand, so the mental health response to respite was much more about finding people interesting things to do in the community, not looking after people which is a bit of the disability respite model, so families were a bit reluctant to access it from that point of view, but when they did, the kinds of care-providing agencies that were there to purchase the services from were set up to do personal care primarily for older people or people with disabilities. They didn't have workers who understood mental health, they didn't have workers who were flexible enough to take people out and do things with them in the community, so the infrastructure wasn't prepared for that kind of demand with the right sort of skilled staff and the right mind-set and creativity to work out how to do interesting things with people during the day so the carers could have a break, so I think it was a bit of - - -

MR PINI (UCA): We're very good at saying the same thing and using the same words and meaning different things.

MS SCOTT: Yes, we've encountered that ourselves.

MR PINI (UCA): I see people have heated arguments, saying the same things, and really meaning very, very different things, so it is very tough for families or individuals as they try and navigate their way through them.

MR KALISCH: Is that an example of workforce constraints? I'm thinking whether that didn't succeed because there needed to be a bit of time to develop a workforce and that was not sort of in the thinking of the policy developers.

MS HELYAR (UCA): And that's the fundamental infrastructure. I mean, infrastructure in some markets is physical infrastructure. Infrastructure in social services is primarily people with a skill set that can evolve over time as our knowledge and the evidence builds around what's effective ways of working with people, and particularly in these areas, it's changing all the time, that evidence of what's good to do. We're starting to build a strong evidence base for the kinds of workforce skills that are needed and that's a fundamental infrastructure that can't be easily funded through an individualised funding arrangement. I guess the other thing is that the market in social services in different to the market for milk and the responsiveness of the market to change and to shifts in demand are different, so there's long lead times. Particularly if you think about the aged care system, there's 25-year-old infrastructure that needs substantial change but the time frame for shifting that infrastructure is long and older people don't have a long time in their life to wait, you know. So I think the way the market operates is very different in the social services field and that needs to be taken into account.

MR PINI (UCA): I was interested in your conversation with Carers Australia about the workforce issues as well because that's critical for us. When the carer was talking about cert III and cert IV - basically don't care what they have - I really agree with her because I can train someone with a cert III or cert IV, a psych, a nurse, a social worker, but what I can't get is the 10 years' or the 20 years' or the 40 years' experience of your son or daughter and the knowledge that you've built up over that time, so regardless of what I bring in to your house, there needs to be some of that exchange, otherwise it's just an array of people coming in and out. It doesn't have a meaning to the relationship that's in there.

The other thing about workforce is we've been invited to tender for certain things that we've chosen not to because we didn't think we could compete for a workforce, in places like Mackay, Emerald, Gladstone, where if we're competing for semi-skilled people in cert III, they can get $1000 a week driving a truck in the mine.

MS HELD (UCA): The other thing about workforce is that it isn't just skill sets, it's actually mind-sets as well and there's still a strong residual institutional mind-set amongst the workforce which, if you're talking about individualised community-inclusive recovery based kinds of programs, it takes a change in thinking.

MS SCOTT: Can I come to the issue of accommodation and so on because you've talked about institutions and mind-sets. This is another devilish topic because people have such different views about it. Understandably, family members often say to us that they would like to have a situation where in the long term, a person with a disability is independent, is able to stay in their own home and have services come in so they can be in a familiar environment, and I have to say that's quite a reasonable sort of hope that people would have. But then other people tell us that there's certain economies that come from having carers being able to move between more than one client. What's your desired model? What's the right model? Are there multiple models? Is there a model where you say, "No, wait a minute, that's now an institution and we're not going there"?

MR PINI (UCA): We've been very strong in dealing with the Queensland government around what we've characterised as forced co-tenancy, where there's a four-bedroom house, there's four people with funding, "Let's move on to the next house," and not going to the issues in terms of what's the evidence that these people chose to live with each other, because if I go to my son who might be the same age, he doesn't get put together, with no say, with a range of other people, even though he might get some assistance from the government in terms of his studies. So it's some of those sorts of things. Our approach is we're not mad keen on more than three people or not mad keen on three people living together. Where the Queensland government has come to is they have a thing called "shared support" and that's about people sharing their resources so they get a better life. How that's been interpreted by some people, as you wind your way through the bureaucracy, is they need to live together, and that's not the case. I can share support with someone else; I don't have to live with them. But equally, not everything in my life is dealt with by someone who is paid to be in my life, nor should it be for someone with a disability either. There are other ways of getting unpaid supports into their life. They are often harder and require some better maintenance mechanisms than paying someone a salary, but they end up with better outcomes.

MS SCOTT: Can I just check that. Is that the ideal, and that's what you're working to now? But you must have larger facilities than three people co-located?

MR PINI (UCA): I don't. I've got $45 million worth of state government funding and we work really hard towards that.

MS SCOTT: Sorry, how much money?

MR PINI (UCA): 45 million.

MS SCOTT: Okay. Do you think WA might have facilities - - -

MS HELD (UCA): I think there are some group placements - - -

MS HELYAR (UCA): Yes, we can check that, but I know that there's been quite a shift. But some of it is also a generational shift, so there are families with people with disabilities where their children have now grown up who might have been in that system for 20 years and they don't want to change, but somebody coming into the system now wouldn't choose that and so that wouldn't be what - - -

MS SCOTT: It would be very helpful for us to have a perspective from people who run services, that is, about - I don't know how to put this - but about the economics of it and the clinical desirability of it, because some people have said that what they would like to do is have separate homes but not just with a fence in between. Other people have said that for a certain level of need, you must have specialists available and it's just not economical to imagine with high-level care that you're going to have people in individual homes, separated all around the city or a town; if you're dealing with people with high-level needs and acquired brain injury, there's got to be four people in a residence. Anyway, you guys must have studied this and thought about the costs of this and the desired costs versus the desirable outcomes and we would welcome getting material on that.

MS HELYAR (UCA): We will get what we can. I know Wesley Brisbane have done some quite different things, integrating housing models with service models where they've provided quite different options for people, so we'll try and get that to you.

MS SCOTT: Great.

MR PINI (UCA): We would support people who came to us and said, "Our two sons and our two daughters want to live together," and we would explore that with them, where we're fundamentally opposed to people just being bundled together for economic convenience, because in essence what it ends up as is people who get funding at the moment tend to be people at the higher end of the needs scale, so you put four people with higher needs out, and you end up with it costing you more than what people planned in the first place and causing you more aggravation.

MS HELD (UCA): One of the issues with housing of course is the availability of appropriate housing stock and so I've been in situations where people have had the capacity to move out, live in rental accommodation and have the support, and they can't find the rental accommodation. By the time they find it and get it assessed, they have lost it. So that's the other side of the - - -

MS SCOTT: That might go back to the issue of the role of government. There are some things you can expect I guess entrepreneurs to be more responsive to and other things they're probably not, so your experience in that would be very useful.

MR KALISCH: Just one question I will leave with you for your submission: given that you are such a large employer across a range of areas, I suppose we would appreciate a sense of where disability fits in in the priority order in terms of the ability to track staff and the capacity of the staff to stay in that sector. We've heard from others that they sort of see disability down towards the bottom of the pecking order, that people would prefer to be in other community services or in the health sector or other areas. I don't know whether that is consistent with your understanding or experience.

MR PINI (UCA): A brief comment: I think it is, in the traditional way of designing a disability service, but if you go to the sorts of things of the Warwick example I gave you before, it's a really attractive role for someone. It's a transformational role in someone's life and you get to do really nifty things.

MS SCOTT: I don't know if you have figures for staff turnover, but I recently visited a centre and people have been there for 12 years, 15 years, so I sometimes try to match stories with reality, so anything you can give us, any data, we'd be happy to take it.

MR PINI (UCA): Ours is about 25 per cent and that's down from an industry average of around 30 to 35.

MS SCOTT: That's per annum turnover?

MR PINI (UCA): Yes.

MS SCOTT: Okay. That would be useful. Thank you very much for coming along today. That was really good. Unless anyone has a last-minute urge to come forward and say something, thank you very much for attending today and I now adjourn the hearings until Brisbane. Thank you.

AT 10.51 AM THE INQUIRY WAS ADJOURNED ACCORDINGLY