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TRANSCRIPT OF PROCEEDINGS

PRODUCTIVITY COMMISSION

DRAFT REPORT ON DISABILITY CARE AND SUPPORT

MS P. SCOTT, Presiding Commissioner
MR J. WALSH, Associate Commissioner

TRANSCRIPT OF PROCEEDINGS

AT BRISBANE ON TUESDAY, 12 APRIL 2011, AT 10.30 AM

Continued from 11/4/11

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MS SCOTT: Good morning, everyone. Welcome to the Productivity Commission's hearing here in Brisbane. My name is Patricia Scott and this is John Walsh, who's joining us by Skype from Sydney. This is our second day of hearings here in Brisbane and I'm pleased to see a number of people back again. So thank you very much for attending. We welcome everyone's attendance of course.

You'll be able to read the transcript of today's hearing by going to our web site pc.gov.au, but it will take probably about three or four, maybe five days to get the transcript up. It does mean that we are recording today's session. So if you are one of the people presenting today, you need to remember that you are being recorded, so you might want to take that into account in terms of what you say. I note a couple of people yesterday made a few remarks about family members. Maybe that's a good thing to do. Maybe, on the other hand, they want to think about the fact that it's now on the public record. So you might need to just keep that in mind.

You don't have to make an oath. There's no requirement under our act for you to give an oath to provide your testimony, but the legislation does require that you are truthful in your remarks. We will, John and I - and in the afternoon myself; I'll be doing this as presiding commissioner by myself this afternoon - be asking questions, so you might just want to take that into account. Are there any members of the media here at the moment? No? Okay. We may find that the media join us at some stage, but I will make sure that, if you're at the table, you know that's the case and just make sure you're comfortable with that.

We have had some people express interest in making a statement at the end of the day. If possible, I might even allow those people to make their short statements between other people at the hearing so that we can still finish on time. At this stage we will have four people in the morning and four scheduled people in the afternoon and I think I've got interest in two people making brief remarks. That's fine. If you did want to make some brief remarks, please indicate soon and then we can take it into account now in terms of our schedulingTherefore, I call out to the table Steve Peek, please.

MR PEEK: Where do I sit?

MS SCOTT: You're going to sit there, just in front of one of the microphones. That would be good. So Steve, you're speaking on behalf of your family?

MR PEEK: Yes, my daughter.

MS SCOTT: Okay.

MR PEEK: Just quickly, I have a three-year-old daughter. She's got quadriplegic cerebral palsy, global development delay, and a couple of other problems, severe epilepsy, and she's bottle-fed. So what I wanted to talk about is that the NDIS is something that we really, really need. What I see is that it focuses, quite rightly, on the individual who has the disability, but I don't think it takes into account enough the carer. One main point is superannuation. A carer can spend their whole life caring for their child and basically all you get is a carers payment; there's no allowance for superannuation. I spoke to a woman last year. She was 52. She said to me, "I've been looking after my son on my own for the last 15 years. What do I do? I've got no superannuation." I think most of us are in the same boat.

If you take a worst-case scenario - say in five years' time, 10 years' time - it's obvious that the government is drifting away from aged pensions and going to rely on super. Now, if you're in your 60s and you've been looking after your child for their whole life up until you're 60, and let's say, worst-case scenario, that child dies, the parent is no longer eligible for the carers pension, they have no superannuation, and, like I said, if it drifts towards where you have to have superannuation for retirement, you'll have nothing. You've committed your whole life to doing a job that would cost the government around $300,000 a year to do. I think that's a really important point, because the carers payment is classed as family income, it affects your family tax benefit - part B I think it is - but I think it's the only income in this country where there's no superannuation.

The second point is a national disability register for Centrelink. Because the whole Centrelink process, right from the word go - like us, in the last year and a half we've had to do three medical reports applying for the carers payment. Every time we do a medical report it gets billed to Medicare. Now, in some cases there can be change of circumstances, but in a lot of cases with disability - like I say to Centrelink, unless they have a magical cure for our daughter that they're not telling us about, her situation will not change. So three medical reports. If you multiply that by the thousands of people, it runs into millions of dollars; unnecessary. Look at how many speech therapy and physiotherapy sessions those millions of dollars can provide for a child.

MS SCOTT: Can I just ask about that, because we have had a meeting with Centrelink and they acknowledged that in the past they would ask people every year, "Does your child still have a disability?" and how grossly insensitive that was when someone had a permanent condition.

MR PEEK: Yes.

MS SCOTT: And they said, "We've realised that that's wrong." I took them at their word that things have changed. So can you explain? If you don't want to, that's fine - - -

MR PEEK: No, I'm more than happy to.

MS SCOTT: - - - because I'm conscious that it is on public record. But was there any logic at all to why they got you to do three medical reports?

MR PEEK: To put it bluntly, they don't know what they're doing.

MS SCOTT: Right, okay.

MR PEEK: I applied for the carers payment for the first time a year and a half ago, and we got rejected because my wife was working at the time. Then her hours got cut at work - because of taking more time off for our daughter - so I applied for the carers pension. So we had to put in a medical report for that, which is fair enough; that's a year later. Probably four months later my wife had to stop work - because it was just getting too much for both of us - because she requires 24-hour support.

So I went in on the Monday to see Centrelink and asked them what we have to do and what we're entitled to, okay? I said, "My wife is going to go on the carers payment." They said, "No, two people can't go on the carers payment." I said, "Yes, I've got it in black and white on our last medical report." They said, "Let me check on my computer." Checked on his computer. "Yes, you can." "So, okay, do we both get the carers allowance or only one of us?" "No, both of you can get it." "Do we need a medical report?" "No."

Came back on the Tuesday, saw somebody different, went through the same process again, through the whole thing. "Do we both get carers allowance?" "No, only one of you gets the carers allowance." "Do we need a medical report?" "Yes, you need a medical report."

MS SCOTT: Even though the condition is clearly - the old category used to be called "manifest".

MR PEEK: Yes.

MS SCOTT: Like, it's clearly the case that there's no immediate likelihood of some substantial improvement, but they got you to do two lots of medical reports in a short space of time?

MR PEEK: Yes.

MS SCOTT: Okay. Can you remember - I won't hold you to the exact month, but two medical reports within a year. Is that right?

MR PEEK: Yes, November to February.

MS SCOTT: November to February?

MR PEEK: But when it came down to actually doing it, I got a phone call to say we didn't need the medical report after we got it.

MS SCOTT: Right. So they realised too late?

MR PEEK: Yes, but it had already been done.

MS SCOTT: Yes, I understand.

MR PEEK: It wasn't actually until I went and saw my federal member - we couldn't get any clarification on anything.

MS SCOTT: Yes.

MR PEEK: Because when you go into Centrelink you don't see a person who's experienced in disability.

MS SCOTT: No.

MR PEEK: You see whoever's available at whatever desk.

MS SCOTT: That's right. I probably took you away from your points, Steve. I just wanted to explore whether things had improved, but that suggests they haven't.

MR PEEK: Not really.

MS SCOTT: Thank you.

MR PEEK: Not in my experience.

MS SCOTT: Okay. Thank you.

MR PEEK: The national disability register - what I see - would take a lot of this problem away, because no matter what you apply for - whatever support you apply for - you have to prove your child's disability for every support network. It's not the best thing in the world to have sit down, constantly tick the boxes - what your child can't do - and prove that they have a disability.

I think it should start right from the point of diagnosis, from a hospital. It would only take one social worker when a child is diagnosed with a disability, because it's a maze of things to try and - the social worker would make contact with that family and say, "Okay, this is what you're going to need. This is where you'll go. This is what you can get." There's no one piece of paper that tells you what is out there and what's available. The only way you find out is from other parents, and a lot of people miss out. I think if it's a national disability register, it could go a long way to solving problems, especially with Centrelink.

The second point I wanted to make is means-testing for the carers payment. It's a very, very generic and indiscriminatory thing. It doesn't take into account children's differing needs: like some kids they have a profound disability, and their support needs are far higher and far more costly than other children. It just - how can I put it? - doesn't allow for the cost of what it costs to maintain a child. I had a division of a hospital - I won't say which hospital specifically - but they work on the basis that to maintain a child like ours it costs a minimum of $15,000 a year extra. There's nothing in the means-testing that allows for an individual child. I know of some people who have a child with diabetes. The child injects itself, but they get the carers payment the same as a person does who has a child with a profound disability.

My next point is on the carers again. The carers payment is $537 a fortnight. When you're on a carers payment you can go and work 25 hours a week. So long as you earn less than $250 a fortnight, it doesn't affect your carers payment. You can go and care for somebody else's child with a disability and get paid 22, 23 dollars an hour for it. That $537 a fortnight, if you worked out how much an hour you get, there's a huge discrepancy between the two. If you could get a carer to come in and look after your child for eight hours a day, five days a week, they would get in excess of $900 a week, but we get $537 a fortnight.

If you're in a position where, like some people are, you can't look after your child and you have to hand your child over to the government, whether it's for emotional reasons, financial reasons - and apparently it's happening more these days - a foster parent gets something like $500 a week plus the carers payment on top. That's what I've heard. I can't quote if that's the exact figure but that's what I've heard. A carer is doing a job that - I've been given the figure - would cost the government around $300,000 a year. That's what it would cost the government to maintain a child with a severe disability. We get $537 a fortnight for it.

I see that there are three main points in looking after a child with a severe disability: you have to provide a roof over their head; you have to provide food on the table; and then after that comes the services like physiotherapy, speech therapy. I think that's the order of importance. You're basically kept in poverty when you're on a carers payment. I cannot understand why there's this big discrepancy: $537 a fortnight as against what?

We can't send our kids to day care because with some of them their disability is too severe. From what I hear, you can send a child to day care but you have to get an individual person to come and look after them. I'm sure it costs the government more than $537 a fortnight to provide somebody to look after that child. I think there's a huge gap there in what we actually get as a carer.

The next one I've got is actually a question for the NDIS. There's a huge waiting list for services, and there's a huge shortage of carers. There are waiting lists for private speech therapy, physiotherapy. The Cerebral Palsy League, who we're affiliated with, they have waiting lists. How will the NDIS alleviate the problems in accessing these services; the waiting lists? The next one is - - -

MS SCOTT: We'll take all of your questions and then see how we go. All right?

MR PEEK: Yes.

MS SCOTT: Because we've got about another five minutes.

MR PEEK: Yes. The disability needs to be nationalised because the state is not doing a very good job of it, and the services and the quality of services vary from state to state. I'm sorry to say, but the state government here is not doing a very good job of it. The next one is: I don't know how the NDIS got the numbers of people with disability. I'm sure DSQ here in Brisbane could not tell you exactly how many people there are in Queensland with a disability. That's something for you guys to answer later.

The other question is: what will happen if the funds dry up? With cerebral palsy alone, there's one child being born every 15 hours with cerebral palsy. Our population is increasing - constantly increasing all the time - which means all the other problems that come along keep increasing too. It just worries me that it's not a matter of if the funds dry up but when the funds dry up. I read in the report that you can cash in on the insurance under certain circumstances. If a person cashes in on that funding, will that then be classed as income by the IGO and reduce a person's carers payment through Centrelink?

MS SCOTT: Okay. Is that the end of your questions, Steve, because I'm just conscious we're going to run out of time?

MR PEEK: Yes.

MS SCOTT: Let's do the last one first. Is that all right, John?

MR WALSH: Yes.

MS SCOTT: Look, we've suggested that - and I'm going to try and deal with them quickly.

MR PEEK: Yes, all right.

MS SCOTT: There's lots more, because you've got the overview, but behind the overview there are 800 pages.

MR PEEK: I'm sorry, but we don't get the time to - - -

MS SCOTT: I know. That's why I'm going to try and do quick answers.

MR PEEK: Yes.

MS SCOTT: If you don't like my quick answers, when you do get a chance, if you ever do, there's more detail behind. I just wanted to tell you that. We suggest that people have a package. So your daughter - it would mean another assessment, but this would be about needs and not about whether you or your wife gets the carer payments.

MR PEEK: Yes.

MS SCOTT: It's about the needs and therapies for the child; just like the Cerebral Palsy would need to do an assessment. Hopefully, what will happen is there would be one assessment. People will say, "Right, okay, these are the therapies that are required. This is the amount of attendant care. This is the respite that the family carers would get. These are the arrangements. Let's think about schooling" - you know, what's the right arrangements and so on? So people would be forward looking. If you and your wife in this - first off, if our recommendations got accepted by government. So it's the first thing. This is not a given. It requires governments to agree to it.

MR PEEK: Yes.

MS SCOTT: Let's say for a moment the governments agree to it. The child has the assessment. Then you could choose either that you want the money to go to Cerebral Palsy and they will arrange the services for you, or you'd like them to go to the North-West Service and they will arrange the services in Brisbane, if you live here, and so on. You'd nominate who the organisations are that you'd like to help you or you could say, "We'll take the package. We'll manage it." Okay? If you take the package and you manage it, or if you just simply nominate the services, we've suggested in our lengthy report that the tax law would need to change or be clarified that that payment was not income for the family.

MR PEEK: Yes.

MS SCOTT: So that one, we've thought about that, we've got that covered. If the government accepted the recommendation, it would not be income for tax purposes, okay? What will happen if funds dry up? This is why we've been very strict in how we've written the scheme, so that there would be clear eligibility for the individualised funding packages. Some people would not get those funding packages. Some people, they might get a referral to a particular place, they might get some assistance in helping them navigate, but they would not get a funding package because the needs don't warrant it.

So we've talked about having the scheme be very sustainable, and we've suggested that, just like the age pension, it would be part of the federal government's budget. So it wouldn't rely on a particular source of income; it would be just out of revenue just as the age pension is. I mean, nobody says, "Wait a minute, we don't have enough. No, there's too many aged pensioners. Right, the last 10 people miss out." They don't do it like that - and that's what we're suggesting here; that it be a core function of the federal government with lots of input from the states.

How did we get the numbers? I'll get John to answer that, because he's an actuary and he can tell you that we got the numbers using the best data we have. You mentioned that you thought it should be a national scheme, so that wasn't so much a question. Waiting lists: there are substantial waiting lists now. If you want to write to us and tell us what the waiting lists are, that would be quite useful, because we do try and include people's personal experiences in here, as you can see. But the reason why we think that the waiting lists should be eliminated is because we're proposing that funding be doubled - so it would go from being $6 billion across the country to being $12.5 billion. That's why.

We think there are actually physiotherapists out there; they're just not necessarily working as physiotherapists or they're not working in the paediatric child area. We know that there are speech therapists, where they're not working. We know there are people who are doing caring as paid work and they've expressed that they'd like to do longer hours. So sometimes the reason why there are waiting lists is not because there's a shortage of things. It's - - -

MR PEEK: A shortage of funding.

MS SCOTT: - - - a shortage of funding.

MR PEEK: Yes.

MS SCOTT: That's why think the doubling would make a difference. John, I might get you to just see if you can reassure Steve about how we got the numbers, and then if you've got any questions for Steve you might ask them now, because then we might need to wrap up quickly.

MR PEEK: Yes.

MS SCOTT: Okay, John.

MR WALSH: Yes, thanks, Steve. We still do need to do more work on the numbers, but we're pretty confident that we have a good feel of the total numbers required. Every - it used to be every six years, I think it's going to be made more frequent - the Australian Bureau of Statistics does a Survey of Disability, Ageing and Carers, and we've analysed that survey. It asks people things like, "How many times a day do you need assistance?" "What do you need assistance with?" It asks people what their health condition is. So by looking at that survey we can get a pretty good handle on what people need.

So we've tried to put some dollars around what we think would be required to meet people's support needs, we've compared that to what's currently provided by state budgets in providing disability services, and that's how we've come up with saying that we think the funding needs to double. As well as having done that work, we're proposing a system where, as you say, there would be the equivalent of a national register, there would be a longitudinal database that would sit with the agency, and we'd keep a pretty close eye on that register so we could follow what the system was costing and manage it efficiently. So I think we've done all that we can do in terms of estimating the cost and trying to make sure, from a governance point of view, that the cost doesn't blow out. But any ideas you've got we'd be very grateful for.

MR PEEK: As much as you can.

MS SCOTT: Okay.

MR PEEK: Look, at the moment there are people who fall through the cracks.

MR WALSH: Yes.

MR PEEK: They're not accounted for. The numbers, I wouldn't have a clue, but you hear stories all the time about people who have fallen through the cracks.

MS SCOTT: We've chosen, on the basis of the data, a larger number than would be getting assistance now, okay? So it's a larger number than would be getting assistance now.

MR PEEK: Right.

MS SCOTT: Steve, I'm just conscious of time. We've got other people who want to present. Are you comfortable if we finish there?

MR PEEK: Yes.

MS SCOTT: Great.

MR PEEK: There's just one thing. Next time you write something up, like I said if you can take into account the carer's superannuation and stuff like that, because I think it's something that's left out.

MS SCOTT: Yes, okay, noted. Thank you very much.

MR PEEK: Okay, thank you.

MS SCOTT: All right, I now call to the table Chris Kynaston. Chris, welcome to our hearing today. I understand you're representing yourself or your family; you're not representing an - - -

MS KYNASTON: Yes. I'm not representing an organisation.

MS SCOTT: You're not representing an organisation, that's right. Just to be clear: we've assigned 20 minutes for your presentation, but you might allow some time for us to ask you some questions.

MS KYNASTON: Yes.

MS SCOTT: Thank you.

MS KYNASTON: Thanks. The reason I came along today is because, in terms of the National Disability Insurance Scheme, I was just concerned that there's a particular group of people that may possibly have fallen below the radar, and I just wanted to make sure that, (a) they were identified, and (b) that their needs were clearly articulated. I'm representing a small group of families - I believe they're small at this point in time.

I was a carer for a number of years, and I was a carer for my husband who suffered from a neurodegenerative disease, a very vicious disease called multiple system atrophy which progresses very quickly and leads to disability within a few years. The average lifespan on being diagnosed is normally six years, and the person typically, in the last couple of years of the disease, is profoundly disabled. By that I mean, in my husband's case for the last year of his life - actually the last four years he was unable to speak because of a loss of control of the muscles. So he was unable to speak. He was totally bed-bound. He could only move his arms and, to a certain extent, his head. He was catheterised. He was fed through a PEG - I mean, really profoundly disabled, and we got virtually no help for all the years that he was ill.

So I was really pleased to see in the commission's report that they're talking about early intervention. That sort of help and assistance would have been invaluable. In other countries my husband would have been considered a palliative care patient on diagnosis of having a terminal disease. In Australia the definition of "palliative care" is very truncated, and there's this kind of - I suppose I found with the report that I'm not even sure if this group of people are acknowledged. I'm aware that they'd come under certain catch-all clauses, but the sorts of things that we were doing, particularly in the last year - I am not a nurse, I don't have a medical background, but I was administering morphine; I was giving injections; I was doing PEG feeds; I was sort of using a hoist to move my husband around.

I suppose the thing I should say about multiple system atrophy, too, is that it knocks out all of the bodily systems over time - as I said, my husband had very little left - but it does not affect cognition; therefore he was as bright and alert and as vibrant as ever, but locked in a body that was cruelly deteriorating. He had an ACAT assessment at some stage, and we were told he was high care. There was no help available, but eventually we were actually given EACH package - extended age care in the home package - even though, age-wise, he didn't qualify. On being overjoyed that we got the EACH package, we then found out that there were no EACH packages in our area and that we would have to wait for somebody to die in order for a package to be freed up for reallocation.

18 months later we did get an EACH package, but the way that package operated was that I think we got 16 hours of help a week. As soon as my husband became so profoundly disabled that we needed a hoist, he then became what's termed "two assist" - ie, you need two workers. So rather than 16 hours of one worker a week, when you really need it, you suddenly find you've got eight hours of two workers. And not only that. I mean, I'm not looking for sympathy. I'm amazed I'm still standing, and I know other people in my situation; I'm not alone here. I know people who have broken down because of the extreme stress of all these medical procedures, and it's your husband or it's your wife or whoever, and you just become like a robot, and I was a robot. So all those things.

If you imagine what you might do when your loved one is dying - like going through family photographs and talking about it - we couldn't do any of that: (a) my husband couldn't speak, although he did have access to a lightwriter. All I did was feeds and injections. I needed to carry on working to meet the financial costs associated with disability. Now he's gone, I'm just left with this giant guilt and in my head I know I did everything possible, but in my heart I think, "Why didn't we look at the family photographs?" It leaves like a giant stain on your soul that will never go away - yes, I've sort of wandered a bit there.

Talking about the EACH package, because my husband had a PEG, it was necessary to dissolve all the drugs he required, and the morphine was oral and there were secretion drying-up drugs called glycopyrrolates, which I would inject, but because the drugs were changed in substance, it meant that no-one who came into our house to assist could actually administer the drugs. It had to be me or my daughter.

Also the carers were not allowed to administer PEG feeds. I understand that's not prescribed by law. It's possible that our provider, I think, was worried about litigation, so we got no assistance with PEG feeds, no assistance with just everyday drug administration. By "everyday drug administration", there were five sessions during the day when I needed to administer drugs. Part of MSA is that the person is inflicted with Parkinsonian conditions as well as the failure of the autonomic system and so there are a whole range of drugs that are involved.

If you give the drugs with the nutrient feeds, the proteins in the nutrients interact with the drugs and nullify them, so what it means is that you have to keep the drugs away from the feeds. In effect, from the first thing in the morning - I would start at 6.00 with the first lot of drugs. I'd be up at 5.00, but the first lot of drugs would be at 6.00 and every couple of hours in the day I'd have to be there because I would be the one that would have to do the feeds or the drugs. If I wanted to go out to work, then my daughter, who is in her early 20s, would take over and she would give her dad morphine and things like that as well.

MS SCOTT: Chris, even when you got the 16 hours of assistance a week, they still weren't going to do the five sessions a day or the PEG feeding?

MS KYNASTON: No.

MS SCOTT: So it didn't actually mean you necessarily got a lot of - you couldn't get away - - -

MS KYNASTON: It was meaningless, because what it meant was I might have a personal care worker in the house but I couldn't leave the house. I might be able to sit down, although I'd have to say, in those days, you learn not to sit down because if you sit down you fall asleep, so you just keep on your legs all the time. It was just the most horrendous period. I thought in an advanced country like Australia - we had been good people, we had paid taxes, my husband was a good man. When we were down and out and we really needed help, there was nothing there apart from a few hours that were totally inappropriate for our needs.

The one time Commonwealth carers phoned me up and sort of said there's a retreat - it sounded lovely - up in the back of Samford Valley, and would I like to go, and I said, "Well, I can't go. I can't go." I explained what the situation was, and they actually, the only time ever, gave me a nurse for a day because only a nurse could do the things that I was doing. The bill for that was nearly $900 for the day; she arrived at 8.00 and left at 6.00. So I guess if that's what my labour was worth, that's an awful lot of money.

MS SCOTT: Yes.

MS KYNASTON: I suppose my concern is that for some of these individuals it's the articulation between the palliative care system, the health system and this new disability system. For me, it's all a bit nebulous. I just wanted to come along and say there are some people out there who are falling apart. I know there are a lot. I mean, the stories of other carers are equally as distressing. There seems to be an assumption that there's a palliative care system that takes care of people, and it doesn't. In the last few months of my husband's life, I was initially told we couldn't get any help from palliative care because he wasn't in the last three months of his life. With a neurological patient, you don't know. It might be three days, three months; it might be three years. You just don't know.

It was only through continual lobbying for help, which came out of my sleep time, that I eventually got his doctor to write and say, "This patient is" - and it was horrible to do, but I had to get him to say, "He's only got months to live." We didn't really know it, and I explained to the doctor, "You've got to do this, because I'm going nuts." And we got that. When we plugged into the palliative care system it offered nothing. I mean, we had access to some respite care. If I fell apart, or if there was an emergency, he could then be admitted to a palliative care unit, but it had to be an emergency situation. Unlike other countries, there was nowhere where I could place my husband so I might have a weekend off. There wasn't anything there. There were no nursing visits because there was no extreme pain involved. Yes, formally there was nothing.

We actually, in the last couple of months, were fortunate enough to get the services of a charitable organisation here in Brisbane called Karuna and they were amazing. They really made a difference, but they were unable to offer personal care.

MS SCOTT: I understand.

MS KYNASTON: But I did have access to a 24-hour line if there was something medical that I was worried about, that I could phone them about. I'd have to say for the vast bulk of the disease it was awful to see not only the dehumanisation and the awful treatment that I found of people with extreme disability - just terrible treatment, even in the hospitals. The more disabled you are, the less likely - you're at the bottom of the list because you can't articulate your needs. At least that was my feeling.

There was a fair amount of abuse as well. My husband presented visually as a dementia patient. There was a lot of drooling. People assumed there was nothing - that he wasn't an intelligent person. But on a good day - he had a lightwriter and when he was able to move his arms effectively he could tell me things, so I knew who the abusers were in hospitals and things like that. It's awful and people think you're paranoid but it happens. I've heard from other people similar things as well.

MS SCOTT: Chris, you've asked us a question. John, would you like to either clarify where the scheme is proposing to start and finish or would you like to ask Chris a question?

MR WALSH: Thanks, Chris, that's very - the word you used was "distressing" and it's at least distressing that this sort of thing still happens. My understanding of the way the scheme is recommended to assist this sort of approach is that on diagnosis of a degenerative neurological condition the person would immediately be eligible for entry for an individual support package and that package would be reviewed in terms of its provision of support as the condition deteriorated. Perhaps it becomes a bit blurry where, as you say, we get to these last three years of life.

MS SCOTT: Three months.

MR WALSH: Last three months of life, sorry, but that would just mean that it would be unclear as to when the funding of the support moved from the disability support system to the health system. I think I can fairly confidently say to you that the way that we've designed the scheme is that all the needs of your husband would have been met.

MS KYNASTON: You mention the move to the health system but for these patients, including my husband, there was no move to the health system because you get to the point where you're told, "There's nothing more we can do," and my husband was at home for the whole time. Apart from emergencies, right through to the end he was at home, and this is the reality for some people. It's these sorts of things. The health system is not necessarily involved. They've already wiped their hands of certain groups of people.

MR WALSH: Okay, so we probably need to do a bit more work on that. We are aware that the notion of palliative care can be a bit grey and that often palliative care is provided in the community, but we've sort of assumed that that was provided by the health system.

MS KYNASTON: No.

MR WALSH: So this really helps us to understand that that's not always the case.

MS KYNASTON: No, there's nothing. There's nothing apart from - as I say, the real help for us was from a charitable organisation. Absolutely zero from the health system.

MS SCOTT: Chris, thank you for coming along today.

MS KYNASTON: Can I just - I know we're - - -

MS SCOTT: No, you've still got five minutes.

MS KYNASTON: Okay. There's just one other point too. I was kind of distressed to see that once people hit the age of 65 they then have to be involved in payment. In my case, my husband died when he reached the age of 66, but before he reached the age of 65 we had paid thousands. I was in debt because of the expenses and we got no assistance at all. We had worked hard all our lives, we had paid taxes all our lives. When we were down and out there was nothing for us. The expenses were enormous. Just to buy an air mattress, a really good quality air mattress that you need to prevent bed sores, you're looking at $13,000. We couldn't afford that. You hire them, so for an air mattress you're looking at $120 a month. An air chair is about $150 a month, suctioning equipment $120 a month. I was paying $3000 a year just on incontinence wear.

We ended up just on the breadline and I was having to work when I'd like to be - you know, I had to work. For me those years were all bed and work, and money going out all the time. So in those conditions it just seems so unfair that when you get to the age of 65 and your family finances have been ravaged by disability-related expenses, you're then up for paying as well. I couldn't work out the logic of somebody who's catastrophically injured under the other insurance scheme don't have to pay - I don't think they should have to pay - but why somebody who's catastrophically impaired from another cause is going to have to pay; to me it just seemed more injustice.

MS SCOTT: I think you're throwing a challenge to us, so let's try to explain the logic. Our terms of reference said that we were not to take into account disabilities as a consequence of ageing and, as you know, the level of disability and the frequency of disability in the population increases as people age, so you get to 85 and most people have got some sort of capacity limitation. If every disability was to be covered at any age, the cost of the scheme would be very large. The fact that most people can expect to age, most people can expect - if you're a man you can expect, in one in three cases, that you will spend some time in a residential aged care facility. If you're a woman, one in two will end up spending some of their life in an aged care facility.

So because you can expect aged care, the idea is that people who work can cover some of the cost of that expected experience, but most of us don't expect to have a degenerative disease that affects us early in life or necessarily expect to have a child with a disability or expect to have a loved one with a disciplinary or expect ourselves to have a disability. Because we don’t expect it and because these things are very hard to estimate, and people would understate the chances of them having it, the private insurance market doesn't operate well in that area, and that's what we've concluded. It's impossible for you to get insurance cover for $300,000 worth of care - you know, the nursing care that your husband would have really needed for those six years or whatever.

So that's why we suggest that there needs to be a scheme, but the chances of getting a scheme up decrease if it becomes all things to all people and if it becomes aged care, so what we suggest in this report is that at the age pension age - which is going to slightly increase over time, Chris - people would nominate whether they get their services from the aged care sector or the NDIS, but funding would come from the aged care sector. You might think, "Well, why bother?" but there are people who reach 85 with resources, that reach 75 with significant resources, that may not have had a disability at any stage in their life and are able to contribute to some of the cost.

We are talking about a scheme here that is not subject to means-testing and is not subject to asset-testing. People would receive the assistance they need. But if it was a scheme that went for their lifetime, without some contributions the cost of that would be much, much more, because older people fall, older people are frail, and the chances of having any scheme would be reduced by its cost being so much more. Okay?

MS KYNASTON: Yes, I understand that, but I still think that in - maybe if all of those costs that families like us have are actually met up until 65, it's not so bad.

MS SCOTT: That's right.

MS KYNASTON: But currently - you know, when I saw that, I thought, "Oh God, what a gross injustice."

MS SCOTT: No, no. The idea is that people would receive what was reasonable and necessary, and the aids and appliances and all the different things you talked about; that people said that there was a clinical need for that; that that would be provided by the scheme; that people would get attendant care, but cognisant of the fact that there were natural supports. But at age pension age, there would be a change, and if people had had a life where they hadn't worked, then of course they wouldn't be required to make co-contributions because they wouldn't have resources to do that. It wouldn't mean they would miss out, but it would be in that sense means-tested after the age pension age. Okay?

MS KYNASTON: Yes.

MS SCOTT: But we have to keep in mind that John and I and the commission have been asked to look at the feasibility of it, and something could be desirable and attractive but not feasible because of - you know, we're a wealthy country, as you noted, and the question is what needs to be addressed first, and the project we have been given is to look at disability for people actually under age pension age.

MS KYNASTON: I understand that, but - yes. I suppose the other thing I'd say, too, is that it would be useful to kind of nullify this whole idea that Australia is a high-tax country, because in fact it's a low-tax country. It's right at the bottom of the OECD countries. In other countries with more generous systems, the taxation is almost double, and that's the bullet that we might have to bite.

MS SCOTT: Yes. People think this is a costly scheme, but I've occasionally referred privately to the size of the last tax cuts, which is much more than the cost of this scheme.

MS KYNASTON: Yes, I agree.

MS SCOTT: Okay. Thank you for coming along.

MS KYNASTON: Thanks very much.

MR WALSH: Thank you, Chris.

MS SCOTT: We've now got Lillian. Welcome, Lillian, to the table. We've assigned 20 minutes for your presentation. I understand you're representing yourself rather than a group.

MS ANDREN: Yes.

MS SCOTT: Great.

MS ANDREN: Yes, just discussing what's happening in my life and what's sort of happened. I absolutely agree with the comments of several other people that there are thousands of people out there who fall between the cracks, who don't fit within the categories, and I am definitely one of those. I have had dozens of agencies come and say, "Look, it really sucks, your life, the way it is but there's nothing we can do to help you. You don't fit within our requirements." But what I'm actually principally interested in discussing today is the carers pension - the carer payment as it's called these days. I'll just read what I've got here.

I'm a 38-year-old woman with a spinal injury. Principally I wish to discuss the current Centrelink carers payment system. I worked for Centrelink for seven and a half years, so have an understanding of the legislative basis of income support payments and the structure needed to provide these support payments. I've noted that the carer payment system has been mentioned several times in the report, mainly referring to the possible need for examination, but no definitive action has been proposed. This is very disappointing, because an appropriate restructure of the payment system for carers could alleviate the pressure on the proposed new system.

Simply put, I believe that without concurrent changes to carer payment rules and requirements, only half the system is being modernised and many disabled and their carers will continue to be severely disadvantaged. Carers payment is the only Centrelink payment you must work full-time to receive. It does not acknowledge that the carer is in fact a low-paid worker with no upper time limits for hours worked and no extra compensation for these extra hours.

There is no job in Australia where an employer can make you work an unlimited number of hours for no extra wages. Salaried workers are paid higher rates to reflect varied hours. Carers on Centrelink payments are literally expected to be on call 24-7, 365 days a year, to receive the payment. They must provide care seven days a week, with no consideration for weekends or downtime. This dramatically increases burnout and stress for carers, causing many to cease working as personal carers, leaving the caree with no help at all.

There are no safeguards for the carer on Centrelink payments; no WorkCover; no OH and S; no job description; no super; no specific days off or holiday or sick pay. Whilst there is an allowable number of days a caree can be out of the carer's care, this time is not allocated in a way that allows the carer to have meaningful downtime that is required in any other job in Australia. Considering how stressful being a personal carer is, it is not surprising that it is difficult to keep carers for long periods. This uncertainty is an ongoing pressure or stress on the caree, whereby we are constantly waiting for our carer to quit because they managed to get a real job and get a real wage.

I have a delightful young, non-family carer, who will be leaving me soon because she needs to earn a decent income to support herself and to allow her to have a future that may include her own home, a car, an education. She loves the job but can no longer delay her own financial future to care for me. Ironically, she really enjoys the work and is planning to continue as a carer, but through an agency, where she will be paid twice as much as she currently receives.

It can be quite insulting and demeaning to the carer to be provided with an income support rather than a wage that acknowledges work performed. The simplicity of a name change from "carer payment" to "carer wage" acknowledges that they are in fact working and not just receiving Centrelink payments; along with the societal snobbish attitude of being a drain on society, rather than the truth: that they save taxpayers millions of dollars a year by keeping carees out of hospitals, nursing or group homes.

While the caree's needs must be verified by professionals to qualify for a carer payment, the carer is not assessed at all. There are no police checks, no minimum qualifications, no home visits to ensure the caree is actually being properly cared for, and no safeguards to ensure the caree is not being taken advantage of by unscrupulous carers financially, emotionally and physically. Every disability worker employed by an agency is required to work within a structure of rules governing those mentioned facts. Why are carees using the Centrelink system not given the same benefits, rights and protections?

The attitude that most carers on Centrelink payments are family members does not reflect current society, nor does it acknowledge the fact that a family already disadvantaged by the financial burden of a disability should not be expected to forfeit the financial advantages of a proper wage for another family member, leaving them further burdened and financially dependent on public moneys rather than wages. If there are no family members willing or able to take on care and live on the paltry carer payment, how are carees supposed to find a good non-family carer who will accept such a low wage?

Caring is hard work. Very few people are willing to work for less than $10 an hour, so the quality of non-family carer is often very low, but if all you can find is a bad carer, many people are trapped into accepting substandard care from unscrupulous people because it's literally better than no care at all.

Carer payments should not be income- and asset-tested. The fact that the carer payment is income-tested sets up a system that eliminates many potential non-family carers due to income from their partner or other employment or assets. There is no other job in Australia where an employer has the right to pay you less if your partner has an income. These carers do a job and, as such, their partner's income should be irrelevant. Would any of us take on a job where our wages were tied to someone else's income and could be reduced without our consent, while still expecting you to do the work? I have personally lost over a dozen potential carers for this very reason. Their partner's income precludes them, or they're going to get something like $10 or $15 a fortnight, and most people won't work if they're not getting paid.

Carer payment is an all-or-nothing payment. You must need a full-time carer, so people who need more than the three to four hours' help provided by agencies like Blue Care but who don't need someone equivalent to full-time work miss out completely. A system that allows for incremental weekly needs - for example, five, 10 or 20 hours - paying the relevant percentage of the carer payment would be more inclusive and allow more disabled to live independently. I'm sure there are many students, stay-at-home parents, active retirees or unemployed who would be willing to provide some care, especially if the payment wasn't income- and asset-tested, and if someone is on Centrelink payments obviously, only to an agreed-upon level, then their Centrelink payment would be affected.

Also, if the pension was paid incrementally, it could allow the caree to find more than one person to provide care, thus reducing the stress on the carer, the caree and perhaps allowing the caree to find different people for different aspects of care needed; for example, housework, yard work or personal care. Obviously, it's almost impossible to find one person who can perform all caring tasks necessary to keep me in my home.

Carers must have lived in Australia for two years before they qualify for a carer payment. Over the years I've had many new Aussies interested in being my carer, but are all disqualified by this two-year rule. Whilst it makes sense to limit other Centrelink payments in this way, it eliminates many potential carers from an already small pool of applicants. Perhaps once someone becomes a permanent resident, they should be allowed to receive the carer payment. The report actually mentions directed immigration for carer roles. This rule change would allow people already here in Australia to do the work.

MS SCOTT: Gotcha.

MS ANDREN: Thank you. If the caree is unable to find a carer, then releasing the equivalent carer pension amount to pay for caring needs would be helpful. This would allow the caree to hire professionals to provide services such as house or yard work. Now, whilst these people would receive more per hour than someone on a carer payment, they would actually be professionals who assumedly would be able to perform the tasks faster and better. This would reduce the time intrusion into the carer's home and allow all appropriate jobs and tasks to be completed properly and to a high standard.

I've been repeatedly told by Blue Care, who provide me with some services, that the people they send to clean my home are not cleaners so I cannot expect a high standard from them. Apparently they are sent only to maintain my home, and this is the exact word they use - "maintain", not "clean" - plus, they are so restricted in what they do that I still have to hire professionals to come in at regular intervals to perform the tasks not allowed and to give my home a decent clean. I now rarely allow visitors because I'm so ashamed of how my home looks and cannot afford private cleaners very often. As someone with a spinal injury who rarely gets out except to doctor's visits, I'm incredibly isolated by this.

As someone who's seen both sides of the system, first as a Centrelink employee, now as a Centrelink recipient, I think I have a unique perspective on the system and will be delighted to discuss many aspects of the system with whomever was willing to listen. I'm willing to travel at my own expense wherever needed, to be given the opportunity to do so, which is not something I offer lightly, considering the severe pain any travel causes me. I would be happy to participate in further phone links. I am a confident and articulate communicator, who wishes to speak for myself and for others not able to tell their story.

So I thank you for your time in listening to me. I have many, many more things to say, but I thought that focusing on the Centrelink payment was appropriate considering I've read almost all of that report and it's mentioned half a dozen times and saying, "We should look at it, but we're not going to."

MS SCOTT: Thank you. John, would you like to make any remarks or ask Lillian any questions?

MR WALSH: Thanks, Lillian, that was pretty clear. I just want to get your situation straight for the record. So you are receiving services from Blue Care?

MS ANDREN: Yes.

MR WALSH: Under the HACC system or the disability support system?

MS ANDREN: Yes. At the moment I get three showers a week. I initially was only getting two showers a week, but the third shower a week is based on incontinence issues, and the delightful irony is, to receive that third shower per week I must have daily incontinence issues. So the system allows me to sit four days a week in my own urine to provide me three showers a week. And I am in Brisbane: imagine what it's like in the heat to go days without a shower. That's why I don't let people come near me, because I'm terrified that I smell.

My house is filthy. I'm already incredibly isolated as it is, and these systems just don't work. Would any of you go to work with not having had a shower for two days in the heat of Brisbane? No, you wouldn't. Why am I expected to? And the services that are provided send - Blue Care come any time between 7 am and 4 pm. There's no definitive time; you cannot make any plans; and, oddly enough, I don't like to go out unless I've had a shower, but some days they're not coming until 1.30 or 2 o'clock in the afternoon. How am I supposed to book doctor's visits and the like without a definitive time? If I can hire the people, they come at the time we have designated, they're the same person so that I'm not having to strip off and have total strangers touching me in intimate ways, and if they don't do the job that I want them to, I fire them.

These Blue Care workers are not paid enough money. Many of them are lovely ladies, but many of them are absolutely useless and we don't have any right to say which person is coming into our home.

MR WALSH: So that service, inadequate as it is, is funded by HACC?

MS ANDREN: HACC, yes, and at the moment I don't have it because I do have my young carer here, but she will be leaving within two to three months to start a new job and then I go back onto - the only home help they will provide me with is 60 minutes every two weeks. Now, I'm confined to my bed. Can you imagine sleeping on the one set of sheets for 14 days? My condition makes me sweat appallingly and I break out in rashes and cysts and boils. I'm expected to have 14 days' worth of clothes and they will come for 60 minutes once a fortnight, and I have begged for them to come at least once a week, to change my sheets once a week, but no. And I am one of these people - I don't qualify for any of these other packages or funding. I've had so many people say, "I really feel bad for you, but there's nothing I can do," and I am - I think you can tell - quite distressed and angry by this system. It's been seven years since I became disabled.

MR WALSH: Can you just explain, Lillian, for the record why it is that you're not eligible for any other National Disability Agreement funded packages?

MS ANDREN: Because I'm under 65 and I'm not mentally retarded. That's what they have told me. Because I'm under 65, I just fall through the cracks. I've heard those words so many times. And the most that they can give me is, I think, two and a half to three hours a week and that's it. I'm not qualified - because I don't have a spinal cord injury, the Spinal Cord Association isn't interested in me.

There are so many of these organisations. As someone who worked at Centrelink - I worked in the pensions section - I knew, I thought, services that were provided and would blithely send my customers off, saying, "Yes, you'll get this help." I had these exercise books, 64 pages; I'm up to my 11th book. I write my notes on everything. Every 12 months I call them again to see if something has changed and nothing ever does. The quality of carers that I can attract on the carers pension - like, would you work 40-plus hours a week for $350 a week? There's no upper limit. If I need 24-hour care they're supposed to provide that for me.

I've had carers who have come in, I had some who lived in. One guy brought his child, his nine-year-old, and expected me to feed him and the child for nothing. He left owing me $2000 in rent, about $1200 on my phone. I actually went without a phone for about six weeks. He stole a lot of things from the other end of my house I didn't even know were missing until six months after he had left. I have carers who come in and think their job is to just sit there and make me a cup of tea and talk. They don't want to actually do any work. I'm not surprised, considering the wage that they get. It's very frustrating.

MR WALSH: You use carer payment to provide the wages for the people?

MS ANDREN: That's what they're paid, the carer payment. I don't have the money - because what happened with me was an accident in a backyard pool, there was nobody to sue. There was nothing wrong with the pool, so I couldn't sue under his compensation - the people themselves. It was a freak accident. I had somebody fall on me and I caught a 90-kilo man above my head and it ripped the iliopsoas muscle off my spine, tore all the nerves so that my spine is sending the signals but the muscle is not actually attached to the spine, so the signals go nowhere. I have neuropathic pain.

I was an athlete. I was an active member of the gym before this happened. I grew up on a farm, I'm pretty darn tough, but this morning I was actually literally vomiting from the pain. I was determined to come today and do this because I've been trying for years to get somebody to listen.

MR WALSH: Thanks, Lillian. It's good we've got all that on the record.

MS SCOTT: Thanks for coming along.

MS ANDREN: Thank you. Let's hope we can actually do something about it. Is there possibility for examining the Centrelink system or am I just tilting at windmills?

MR WALSH: Income support is not something that we've been asked to look at. Patricia, do you want to say anything about that?

MS SCOTT: Lillian, I went back while you were talking and was desperately looking at the terms of reference to see what we could do. We'll have a look. I don't want to make any false promises. In your 800 pages of reading I'd like to think that you saw things in that proposal that would make a difference.

MS ANDREN: Absolutely, but I'm pretty sure I don't qualify.

MS SCOTT: Well, actually this is not the place to do an assessment but if you have mobility issues I couldn't see why you wouldn't be eligible under the first criteria, so I would have thought - and we've talked about individualised packages. In the press conference I told journalists that it seemed pretty shocking in this place, in Australia, that people didn't get more than two showers a week, so I'd like to think that we're on the same wavelength in terms of the type of packages that people would get.

Whether we can get into the carer payment is another matter, but if you got a package - if this comes up - like, first off, if the politicians accept it, right? - it's not within our remit. If the politicians accept it and you had mobility problems and you met the criteria - and we've set that out in there; you could see quite clearly if you met that. A person would get an individualised package. They could decide who they wanted to provide them services or they could hire people themselves, and I would have thought that whether we get to do something on the carers payment or not, if you were able to get an individualised package that took into account your needs, you would be doing better than 60 minutes every two weeks.

MS ANDREN: Yes. The situation with me as well, because I have limited mobility - I can walk for short periods of time - that seems to take me out of other qualifications, and of course I'm incredibly grateful, because I couldn't walk to begin with. They told me to go into a nursing home when I was 31; that I'd never walk again. I'm thinking, "Don't tell me what I can't do," and I proved them wrong.

But I think one thing that's important that we should all consider: in Australia, if you choose to buy a house they will give you $14,000. If you choose to have a baby they will give you $6000. I didn't choose to become disabled and I get nothing. I'm on a super pension. I pay the exact same tax as everybody else. Once I turn 60 my super pension is non-taxable but at the moment I'm paying the same tax as a wage and salary earner with zero deductions because I don't have any of the work based expenses. Unfortunately, I can't consider pillows, nighties and walkers as working expenses.

I think this is great. I hope that they actually do accept it and I'll be doing my darnedest to get in contact with my local politicians to make them do so, but hopefully we can actually get somewhere with this system.

MR WALSH: Lillian, just for your own satisfaction, I suppose, it would be worth you reading the chapter on eligibility. I agree with Patricia that we're not doing an assessment right now but initial observations would say that you would be - - -

MS ANDREN: Yes, it would seem that I would get a package under this and that would be fabulous. To have some self-directed control on who was in my home and when and where, and that sort of thing, would be great. I think it's a great system and that's why I actually wanted to speak about the Centrelink payments, because it is mentioned - I've read nearly every page of that 800-page report. It is mentioned, a sentence here and a sentence there, that it should be examined, but it's not. It's not going to be. So maybe this is something that you guys can do. You're the ones who are speaking to the people who are giving you this directive. Maybe you can speak to them and say that this is a second issue that needs to be examined concurrently because if we can get decent carers maybe I wouldn't need a package, and vice versa. Families who are already incredibly disadvantaged by the financial aspects shouldn't be expected to have someone going from $600 or $700 a week to $350 a week.

MS SCOTT: Thank you very much.

MR WALSH: Thank you.

MS ANDREN: Thank you for listening to me.

MS SCOTT: Would you like to come forward now?

MS SAUNDERS: Hi, my name is Christine Saunders. I'm here representing my daughter. I'm a full-time carer and so is her dad. Bonnie has a disability where she has mobility problems, she doesn't speak. That's something that's incredibly important to me because at this point still in a lot of courts she can't be represented in court, or she can't stand and accuse someone, so her case wouldn't be heard. I see those as issues that need to be looked at as well, under this, for the protection of people that are non-verbal or limited verbal.

What I hear today is what I hear at every meeting that I go to, every conference. It's so hard and it's so - the carer's aspect is. I've given up my job, my husband has given up his job and, as Peter said earlier, you go from two jobs to one job to no jobs. We have been successful in getting a very small package for Bonnie but that package can't contribute in any way towards the mortgage which is keeping the roof over our heads, which is vital.

We were in a position last year where it looked like we were going to have to sell the house. The fact is that on the pension we haven't got enough of an income to rent on the open market. I put in an application for housing and they said, "It's no good putting an application in because you own your house." My situation was then, okay, we can't afford to rent on the private market, there is no housing department available, we have to sell, I'll have to relinquish my child because I will not put her at risk in a caravan park. I see the mishmash of funding. I totally respect that a carer - we work for nothing, and we work hard. It's 24 hours a day. You lose your dignity. You become a function. You stop being a person at some points.

One of the questions about the package: if it's self-funded and we have someone regulating it for us, can we contribute some of that money towards the mortgage because it's Bonnie's home, and even sign the home over to Bonnie? I just think that this is a consideration that may need to be looked at for the long-term security of families, and also in the case of renting, if you're in the Housing Department even. It's a lot of money out of the home if a part of the funding can contribute towards basic household costs.

MS SCOTT: That's a good question. John, do you want to have a go at answering it?

MR WALSH: The idea of the scheme is to meet the support needs of the person with the disability. I guess what we would expect to happen is that your restrictions on employment, and those of your husband, should be largely lifted, or at least lightened, by the existence of the scheme so that you would then be able to go back to work. That's the hope of the scheme. It's not the intention of the scheme that it would pay mortgages. However, for people who do need (audio cut-out) a place outside of their family home, we have got in there an allowance for the capital cost of those accommodations; not for the rent but for the capital cost. I think it would depend on individual circumstances, but certainly for a person with the support needs that you've described your daughter as having, I think the system would provide you with enough options so that some of the financial pressure was lifted.

MS SCOTT: We do say that we see merit in the states considering cashing out public housing so that people can have more choice, and we do talk about supported accommodation. I don't know if that's the sort of accommodation that you - - -

MS SAUNDERS: My daughter is too young; she is only 12.

MS SCOTT: All right.

MS SAUNDERS: So her accommodation would be a nursing home.

MS SCOTT: All right. I see.

MS SAUNDERS: For the last 30 years I've been involved with disability and I've worked helping people with disabilities. I have a situation where I gave up my job to look after my child because, in actual fact, there are no care facilities suitable or arrangements suitable. It has to be addressed at some point that the carer's function is important. It's not a monetary function either. It's an important function, because I was told there was no hope for Bonnie: she would never walk; she would never talk; she would never - you know. As I said to the doctor at the time, "Don't ever say 'never' to me." He said, "Just get over it. Accept the fact she has a disability." And you go, "No." As a result, she is walking, albeit she needs support at times. She has a couple of words, very sing-songey, but she's this very intelligent child. She is delayed in behaviours.

There has to be a point where the whole picture is looked at - the whole family, the whole unit - even if parents are means-tested: "Are you qualified to do the work you do?" - but that should never happen, because we are, because we're doing it, because no-one else will do it. I come from a very large family and they're all in Victoria. I'm up here because it's better for me up here. They don't understand. Even family members don't understand. There's a very negative force with that, in opinions on disability: comments like, "Just put them into a home." There is no home. But Bonnie's not a ragdoll. She's not something that I had to give away. She is a very much loved member of our family. There have to be ways to make sure that we don't fall apart.

The early intervention that you've suggested is excellent, and building on that; getting in early respite for families, even though it's intrusive to have someone come into your home. All of those really early things are so important, and also the developmental intervention that can come in by providing services, which is all what you're setting out to do, and hopefully it's all going to come through.

We need to look at broadening the overall value for families staying together. We're unusual because we're together. Peter and his wife are unusual because they're still together. Normally, with children, the families break apart, and a lot of it because of the financial constraints.

MS SCOTT: Yes.

MS SAUNDERS: There has to be a broadening of what you are working for, which perhaps needs to - as someone said, the next Productivity Commission charter is to address the lack of infrastructure, the lack of support systems for carers, the lack of early intervention for carers, so that carers actually cope and get through it. Sometimes I feel so disabled, because I haven't slept all night, that I think I should really go on a disability pension myself. I'll get better paid that way.

MS SCOTT: I understand.

MS SAUNDERS: Thank you.

MS SCOTT: Thank you very much for coming along.

MS SAUNDERS: That's all right.

MS SCOTT: And thanks for that testimony. John, I think we'll now break for lunch. We'll resume our hearing at 1.30. So thank you, and we'll see you back at 1.30.

MR WALSH: Okay. Thanks, Patricia.

(Luncheon adjournment)

MS SCOTT: Good afternoon. We're going to resume our hearings now. Welcome back to the Productivity Commission inquiry into disability care and support. I ask Kerry Splatt to come forward to the table now, please. Welcome to this hearing. I'm sure you appreciate that we've got a transcript happening at the moment.

MR SPLATT: Yes.

MS SCOTT: That your words will be on public record. I understand you're representing just yourself. Is that correct?

MR SPLATT: That's right, yes.

MS SCOTT: Okay.

MR SPLATT: I'm a solicitor, and I've done the submission just on the common law.

MS SCOTT: Yes.

MR SPLATT: Luke is a solicitor in my firm, and just if there are any technical questions that you want to ask, then he's just - - -

MS SCOTT: All right. Luke, we might just have your surname, just for the record, in case you speak.

MR RANDELL: Randell.

MS SCOTT: Thank you very much. All right, Kerry, I think we've got 20 minutes assigned for your time, so please start now.

MR SPLATT: Thank you, and thank you for allowing me to address the commission. As the brother and uncle of two disabled persons, caused by medical negligence, and as a solicitor who acts for negligence claimants, I support the primary view of the commission that there should be a no-fault scheme for care for properly assessed and disabled people.

A wealthy country like Australia should have such a scheme and no reasonable person could oppose it. However, I strongly disagree with the commission's unfair criticism of the common law. Firstly, I think it was ultra vires the terms of reference. The terms did not encompass a review of the common law and did not encompass a review of other heads of damages, which is proposed for 2020.

The common law is complex. It varies according to jurisdiction. It has mostly failed in jurisdictions such as New South Wales because of poor regulation of its legal profession and poor responses to these failings of the legal profession and the common law in that state. Also, the legal profession in that state has failed to be proactive to the problems confronting the common law and the profession.

There has been a spectacular dysfunction between the profession and the government to the detriment of its citizens, and mainly to the Australian taxpayer who has been lumbered with the cost of injuries because of inappropriate use of thresholds. However, the post-IP performs hopefully should be allowed to address a lot of the problems historically occurred which have occurred in New South Wales.

Unfortunately I think the commission appears to have judged the common law of Australia entirely upon the unsuccessful New South Wales regulatory schemes. It appears to have used pre-IP reforms anecdotal evidence as a fact. It doesn't appear to have any regard or reference to the post-IP reforms. The common law deserves a much better and more thorough analysis than the New South Wales experience. It appears to have been written by the architects of the failed regulatory schemes of New South Wales.

Unlike New South Wales, the common law in Queensland is successful. I have served on a number of committees of the Queensland Law Society and the Law Council of Australia, and in particular the Torts Task Force which worked collaboratively with Queensland Treasury, insurers, the Attorney-General's Department, the AMA, and other major stakeholders in insurance law.

None of the excesses and abuses referred to in the report would occur in Queensland because of the post-IP legislative reforms. The profession in Queensland has worked proactively with government and insurers for many years so that claims are handled cost- and time-effectively with satisfactory outcomes. The Legal Services Commission vigilantly deals with any abuses, and costs are contained. The Legal Services Commission has not highlighted any need for any further reform in relation to solicitors' costs or further consumer protection. The common law is of great value to the Australian taxpayer because tortfeasors' insurers pay the cost of the entry, not the Australian taxpayer.

I strongly disagree with the commission in its findings that the common law is not a deterrent to unsafe behaviour. With respect, it is the major reason for safer outcomes in WorkCover and public liability matters. Higher premiums must have a big impact. The commission, with respect, only looked at motor vehicle schemes where the premium doesn't increase for unsafe drivers. Perhaps it should recommend increasing the premium for unsafe drivers. It surely must go without saying that this would surely lead to a safer environment.

I was astonished that the commission could recommend the New Zealand no-fault scheme and the failed regulatory schemes of New South Wales as models for a no-fault system. They have failed spectacularly and yet the commission recommends modelling on those schemes. Those schemes make injury claimants social welfare recipients. I am absolutely sure that Australians injured through the negligence of others don't want to be social welfare recipients and don't want to be a burden on the Australian taxpayer. They want their damages tailor-made to their individual circumstances and their economic loss and other heads of damages determined on a common law basis by fair judges' decisions rather than on an arbitrary bureaucratic process.

They and the taxpayer want the tortfeasors' insurers to pay and not the taxpayer. The New Zealand scheme is currently $10.5 billion in deficit. Extrapolate that to Australia and it would be $52 billion in deficit. It is amazing that the commission could recommend such a scheme. It is outstanding that it is based on the failed common law schemes of New South Wales. I have to say, I think that the failed common law schemes of New South Wales seem to be more about hatred of lawyers, which is understandable for New South Wales because they haven't behaved well, rather than good policy. I don't know what the current figures are at the moment but I do know that historically in Queensland administration costs under the statutory scheme are more than the legal costs under the common law scheme. Several years ago the administration costs in WorkCover were about 15 per cent of the total costs as compared to 11 per cent for common law. Also several years ago I was aware that there was a 78 per cent approval rating of WorkCover by employees and 79 per cent approval rating by employers. No thresholds means that the tort fees and not the taxpayer pays and huge amounts of statutory refunds are remitted back to the government.

MS SCOTT: Huge amounts?

MR SPLATT: Yes. My small sole practice alone would remit over $1 million back to the Australian government, so the taxpayer is not burdened with the cost of the injury. Surely the commission should be exploring the benefits of the common law to the taxpayer and the better outcomes to the injury claimant, based on the very successful Queensland experience rather than the failed state of New South Wales and New Zealand, which is very expensive to the taxpayer and leaves the injury claimant very unsatisfied, with unjust outcomes. They are utter failures.

I implore you to investigate the very successful outcomes of Queensland common law and that you recommend replication of Queensland throughout Australia and not be so New-South-Wales-centric, that you recommend the abolition of thresholds and the introduction of the injury scale valuation process which occurs in Queensland for general damages, and that you leave the all-important economic loss and other heads of damages to the post-IP common law so that millions of dollars goes back to the federal government which will be needed to fund the no-fault care for the disabled.

All jurisdictions which have thresholds, I believe, are welching on the Australian taxpayer to the extent of millions of dollars. Thresholds are grossly unfair to the injury claimant and also to the taxpayer. I implore you to examine abolition of thresholds and to adopt the Queensland ISV scheme rather than recommending the abolition of the common law and thus burdening the Australian taxpayer. That's it.

MS SCOTT: Thank you. One of the points that was made in the report was the length of time between injury and then usually settlement. Do you have any figures, Kerry, on the experience for your firm about the length of time?

MR SPLATT: The average matter would be concluded within about two years from the date of accident. The only reason for the length - it could be shorter but doctors require at least a year to have occurred since the date of accident before they can assess permanent impairment. Of the number of inquiries that come to my firm I must say that only about 6 per cent we would take to common law and very rarely do we proceed to court. That's because the legislation in Queensland has time- and cost-effectiveness with severe consequences for delay or not being cost-effective.

MS SCOTT: So the 6 per cent you take to common law - I just want to clarify, the 94 per cent are?

MR SPLATT: They would have poor prospects regarding - - -

MS SCOTT: Success?

MR SPLATT: Establishing liability or their injuries are not permanent.

MS SCOTT: For those that clearly have an injury but not necessarily a strong basis for suing someone, whatever that percentage is, you'd be comfortable to see them in the NDIS, the other scheme?

MR SPLATT: Yes, I'm in favour of care for no fault.

MS SCOTT: Okay. So where a fault based case can't be brought you'd be comfortable for them to go into the NDIS? I just want to clarify things.

MR SPLATT: Yes, that's right.

MS SCOTT: All right, I think your submission is clear. Thank you very much.

MR SPLATT: Thank you.

MS SCOTT: Thank you for coming along.

MS SCOTT: Could we now have Jude Mannix, please? Welcome, Jude. We've assigned 20 minutes for your presentation, but you might allow some time for questions, if that's all right.

MS MANNIX: Yes, sure.

MS SCOTT: Okay. Start when you feel comfortable.

MS MANNIX: I've prepared this submission in response to the Productivity Commission's draft report for disability care and support. The proposals outlined by the commission in the draft report are excellent and timely and provide a framework for a better system. People with a disability count. I'm addressing a few different sections here, so I'm just going to head up the section that I'm talking about each time.

Section 5, Assessing Care and Support Needs: the outline in figure 5.2 seems a fair and reasonable process. In fact it seems very similar to the one we have just been through with Disability Services Queensland. What I struggle with - and as many of the comments by others in a similar situation published in the overview booklet that goes with the draft report also seem to indicate - is that the process can be arbitrary. For instance, our son has attended special school for his high school years and before that had accessed special support programs throughout primary school.

He has had a WISC-IV test and others performed by a trained psychologist, which indicated a very low score for intellectual ability. There is obviously a problem, yet despite these facts we've had to go through a form-filling and interview process whereby the focus seemed to be more based on whether we as parents were coping with his disability, not what he needed to participate as fully as possible in the community. That my son was not even present at the interview raises serious questions as to who the support is really for. Apparently we now have a more streamlined process to go through when we reapply for funding this year: no forms, only a two-hour interview with me.

MS SCOTT: And that occurs every year or will occur every year?

MS MANNIX: You only have three goes in Queensland to apply. We've been knocked back the first year. This is the second year we'll be applying.

MS SCOTT: Then what happens if you got knocked back three times? That's it?

MS MANNIX: That's it. So after this interview for reapplying for the funding, just with me - I consider this to be fairly subjective. Surely a report by a trained professional psychologist, doctors and the like are enough to establish the reality of the disability and the level of support needed based on standardised levels. Because I refuse to put on an act - as others have advised - we, as parents, must be coping. This is wrong and disadvantages my son. I hope that within the framework proposed in section 5 and outlined in figure 5.2 the commission has considered ways in which to reduce human bias and assess real need impartially.

Section 8, Delivering Disability Services: I agree with the importance of not developing overly complex standards. In addition, I agree strongly that a service provider can be very good at filling out forms yet not necessarily good at providing a service, as we have already experienced this situation. A forum whereby those within the system can log on and share their experiences would surely add to the controls proposed. Of course this forum should be monitored, but it would be very beneficial to those accessing disability services to have a central place to communicate with one another that is not open to the general public.

In addition, when designing the national Internet database - an excellent and much-needed tool - the inclusion of simple graphics and text instructions on the web site would be beneficial so that those with intellectual disabilities could participate. We have many talented and creative people in this nation. A collaboration between some of them and a cross-section of those with a disability and their carers to develop an interactive and accessible web site is surely possible and within reach.

In table 8.1, Potential Indicators and Sources of Evidence about Service Provider Quality, there is a listing "staff qualifications". Although I agree that staff should pass the usual checks for those working within the sector, the qualification listings concerns me. I've noticed that sometimes people who work within this sector may not be good at spelling, may not have qualifications, may not be very good at administrative tasks; however, they are patient, kind and genuinely enjoy working with disabled people. These people should not be penalised for not meeting certain educational standards. As long as the service provider has in place systems to ensure these people can do their job within the appropriate safety and other guidelines, then the level of qualification surely should not be of major importance.

In section 8.4 the discussion focuses on the need to move to funding based on individual packages. Although I strongly agree with this, it is concerning for those who miss out on funding as my son has. We are personally paying for him to attend a service provider at significant personal cost, as the alternative of him being at home every day is not acceptable. However, the provider has cut the cost to us to the very bare basics, obviously not factoring in their basic overheads and so on. From my understanding, they have been able to do this as they get a small amount of block funding, although most of their funding comes from individual packages. Although paying for our son's continuing development ourselves is extremely difficult, we would not even be able to consider it if we had to pay the full cost.

Section 12, Where Should the Money Come From: Financing the National Disability Insurance Scheme. The discussion in section 12 is comprehensive and the suggestion of a levy makes sense. However, I agree with some of the comments that if structured in a similar way to Medicare as a flat rate tax the poor will pay more. Also, it would seem that in the current political climate a levy would not be a popular addition to the tax burden and it's difficult to see how the current players will implement such a tax. Funding for disability needs to be separated from politics.

The draft report sets out the taxation revenue for the nation and the states. What I struggle to understand is why such a vital and necessary service is so underfunded. According to figures published by Austrade, Australia now has one of the highest per capita incomes at $54,869, and when measured to comparable nations - such as the UK at about $36,300, the US at $47,100 and Canada close to $49,000 - clearly we are doing well. As well, the draft report has minimal economic modelling of what the outcomes would be if those with a disability were better supported.

For instance, to adequately care for our son we have to pay for him to go to a service provider for three days a week. The other two days are a juggle between each of us. Usually he goes to work with my husband - not the best of situations - and often this means he is just sitting around for the day, or I will try and work from home, although this is also difficult as I have to design a program for him to follow for the day and ensure he stays on track. Obviously our current situation negatively impacts on our productivity and our economic contribution.

Also, our son's eventual capacity to work is not fully accommodated in our current situation. A study in 2002 of over 600 Australian businesses indicated that over 90 per cent of employers who had employed someone with a disability would do so again. As well, 90 per cent of employees with a disability had productivity rates equal or greater than other workers; 98 per cent had average or superior safety records; and 86 per cent had average or superior attendance records.

Yet despite these great statistics, the Australian Bureau of Statistics reports that for those who have a disability that restricts employment, participation in the workforce is only 54.4 per cent, as opposed to 81.9 per cent for those without a disability. If those with a disability were better supported to join the workforce, then they could add to the nation's productivity, as well as participate meaningfully in society as so many of them want to.

In section 17, the implementation: although I understand the reasoning behind the time frames and the rollout of the scheme in seven years, our son will be 27, we will have battled on alone in our efforts to provide a meaningful future for him. Surely there is scope for a quicker response.

In conclusion, the idea of a National Disability Insurance Scheme is welcome and needed. However, if some of the issues regarding how the scheme is to be funded are left to political will, I feel that the outline provided in the overview booklet - the cameo one of the young person with an intellectual disability - is a dream that I will never witness.

I, like Anthony Macris - the author of the book about A Family's Journey Through Autism - want to believe Bill Shorten when he says we can do better for those with a disability. I, like Anthony, worry that my son will not be adequately cared for if something were to happen to either myself or my husband. I want to believe that our rich nation will not continue to let the most vulnerable members of our society down.

MS SCOTT: Thank you very much. That's very clear. I just wanted to clarify one point that you made. This is very well-presented material. You have the suggestion that there could be an online forum where people could share experiences. About the quality of particular providers, or just about experiences so that they could learn from each other?

MS MANNIX: No, I was thinking about, in your report, how you planned to put a listing of the different providers and then some discussion, a red flag and so forth, about them; that if there was access to people who were in the system to be able to discuss with one another what they thought of that particular provider. That's why I said it should be monitored, to make sure that things are fair.

MS SCOTT: All right. One more question, just for clarification.

MS MANNIX: Yes.

MS SCOTT: Individual packages - this is in section 8.4 and on page 3 of your notes.

MS MANNIX: Yes.

MS SCOTT: At the moment your family is meeting the cost of your son's three days a week to go into some support and you say that you've been able to do this because the provider has some block funding. If your son - you say he has a significant intellectual disability. I'm not an assessor, but if this scheme got up, he would in all likelihood get an individualised package. You wouldn't need to rely on block funding if you had your own package.

MS MANNIX: Yes.

MS SCOTT: I'm just trying to work out why you think there would need to be both.

MS MANNIX: The only reason behind that is that we are ineligible for funding.

MS SCOTT: Yes, but we're talking about a future system.

MS MANNIX: Yes, I know, but if we already have a system where there's not enough money for some people to have funding, there's a possibility that that could happen. That's just a reality and it would be great it if wasn't, but in the case of that being the reality, and somebody being considered not as in desperate need as somebody else, maybe then there needs to be some way of managing that.

MS SCOTT: And your last observation, that the outcome of our inquiry is a matter of the political will, that's undoubtedly the case, given our democracy.

MS MANNIX: That's right.

MS SCOTT: All right. Thank you for coming along today and thank you for that presentation. It's very clear.

MS MANNIX: Thank you.

MS SCOTT: I'll just explain to everyone, Lesley - - -

MS KEYES: Lesley Keyes.

MR SEYMOUR: Geoffrey Seymour.

MS SCOTT: Lesley and Geoffrey would like to make a short statement. They are not booked into our schedule but, because we're just a little ahead of time, we're going to give Lesley and Geoffrey a chance to make some comments now and they will go into the transcript. If it doesn't look like we're following a schedule, we're just taking advantage of the fact that we've got a little bit of time.

MS KEYES: We're not very well prepared.

MS SCOTT: That's all right. We understand that they are off-the-cuff comments, so that's fine. Lesley, when you're comfortable, if you could just say your name into the microphone. Let's say we've got five to 10 minutes. See how we go.

MS KEYES: My name is Lesley Keyes. I've been an amputee for 37 years as a result of an accident involving a drunk-driver; I was 18 at the time. I have other experience with disability services. My 22-year-old nephew is severely intellectually handicapped and has qualified for payment to attend like a workshop. My brother and his wife pay for one day a week. I don't know why there's that sort of disparity, but I just bring that example forward.

I've also recently lived in New Zealand for five years, as an expat, where my husband was managing an Australian company, and I have experience under the ACC system, which was the best available options and service I have ever experienced in 37 years, unquestionably.

There is a problem with the ACC and it's specific to New Zealand, and that is that they do not adhere to the occupational health and safety in the same way that we do in Australia, and there is a culture of using labour cheaply. Therefore, a lot of people have to take advantage of the ACC and cause a lot of extra stress on the system. So, as a role model, in my experience it is excellent.

The public purse: I'm going to be colourful here, but I see that through remorseless pawning, sycophantic and ingratiating tactics, and a profound lack of conscience, an advantaged socioeconomic group - and that is the medical fraternity and the legal profession - continue to exercise superior entitlement to public funds over that of the generally disadvantaged socioeconomic group who must endure ongoing hardship and fractured lives. The money belongs with those in need. After all, isn't that what the governments have the voting public believe when they boast about their budget allocations?

Without argument, the current situation is defeatist, patronising in both its terminology and its systems. I find the terminology incredibly disparaging. Attitudes of politicians and their minions need to change. Also the public needs re-educating. Successive generations have seen a loss of common courtesy and civility. This is evidenced in the flagrant misuse of disability parking spaces. How many times have I had to deal with that, and how unapologetic are the people who use them?

On that, people need to understand that the symbol may have a wheelchair; however, the ambulatory disabled battle on with very little sympathy because they are vertical, and the little energy that they have - particularly in Queensland's oppressive weather - to have to hike through a carpark carrying your groceries or your shopping, in the heat of the day, it just takes whatever energy you have to be self-sufficient away from you. So that must be addressed in Queensland, and it cannot be taken away or there will be a war. If I see one more pram carparking space allocated in a shopping centre over disabled spaces I am going to start doing something about it.

I think that not only the politicians but the public need to be educated that the disability symbol doesn't apply solely to wheelchairs. It's very important. I think there should actually be an advertising campaign. I think it would be money well invested. They advertise for everything. Look at the money spent on elections. Look at the money spent on drink-driving. Look at the shock tactics of that. Why can't we have some shock tactics: "This could be you or your family." Let's have examples of people, children, born with deformities or incapacities. The family, what's involved for families: it destroys not just one life. It doesn't take away just that potential, it takes away the potential of all those who are supporting that person for very little, for love. So I think some sort of education or advertising would be great, to help a generation lacking in civility and manners to start to appreciate that we're all just people and that this could happen to anybody.

I have a new paradigm. I'd like the government to assist the incorporation of various disability associations, to create an overarching holistic identity or advisory group, to focus upon their common issues. This is very much in line with what the previous lady was speaking about. So this would govern all current systems, after condensing and combining all the duplications. I think that increased efficiencies would happen as a result. Decreased costs, which would mean more funds available for the end users - so much is sapped up along the way; so many greedy hands - and free of political inconsistencies and machinations. It would free it of that.

The other thing is that this would create a client-focused continuum which orchestrates care and support seamlessly. In 37 years, no-one knows me or my history. I'm a person who has not wanted to rest too heavily on the system. I've wanted to be independent. I have supported myself and wanted to support myself into my old age in my life.

I have tried - perhaps tried too much - to look normal and be accepted as normal in society and tried to avoid the prejudices that seem to befall most people with disabilities. I'd like to see, with the language changing - the language that governments use and that people use in relation to disability - I'd like to see an evaluation based upon a hierarchy of competencies rather than incapacities. This would suddenly change everybody's perception.

We've seen so many people talk here so articulately and intelligently and put their case forward, and they're sitting here with their broken bodies, with their intellect fully intact, and these people still are struggling every day just to survive, just to be like everyone else can be. The effort it takes people to get through every day - when they sit here and they present themselves so beautifully dressed, and if you understood how long it takes every day for some of these people to get themselves together, get in their wheelchairs, dressed beautifully and come with their beautiful faces and smile and speak to you all, and be so gracious to such a greedy shameless society - that's moved me. So if we took evaluation now as being based on a hierarchy of competencies we would liberate the client, the patients, from the disenfranchisement and the stigma of victimhood and allow both self-perception and public perception to shift from a negative to a positive. We're just all people.

Finally - I have one more thing and this also has been raised by the previous lady - I'd like to see the mentoring by government of disability organisations to become competitive, profitable businesses providing opportunities and jobs for the disabled and others; so, more business focus and promoting a positive, socially inclusive and integrated image for the disabled, with particular emphasis here on occupational health and safety.

MS SCOTT: Thank you very much, Lesley. Thanks for coming forward. Thanks, Geoff, did you want to say anything?

MR SEYMOUR: Thank you, Madam Chair. Geoffrey Seymour is my name. I'd just like to make a few comments. As you'd be aware, I've sat here for nearly two days now listening to the various stories from various people with various disabilities. I must say I'm outraged, absolutely outraged, at what I have heard here. I think you have an excellent opportunity to right a very bad wrong and I think the public expects that to happen. Whether the politicians will listen to you I don't know but, if they don't, I can assure you there will be some very loud voices from the floor telling them that they've got to do something about it.

For people to be in the situation that they are, not having help even to wash and clothe themselves, is just beyond belief. I just don't understand it, not in a society like we have in Australia. The whole system to me is designed to make the disabled and the disadvantaged the poorest people in the country. We are subject to means tests, et cetera, to make sure that you can't go ahead, even if you've got the ability to do so. If you've got a disabled problem and you try to get into the workforce, it's very difficult, because the person that's going to employ you has a problem with occupational health and safety in terms of their liability if you get hurt or something happens while you're working for them.

I think this needs to be addressed in a national scheme where the government indemnifies employers that employ disabled people to do a job of work. What we've got to do is make these people feel worthwhile. People don't feel worthwhile if they're sitting at home in their own urine 24-7. There's no way that can happen. So we've got to do better and we've got to make sure this thing doesn't continue the way it is. We have many situations in a number of organisations and perhaps what we should do as different organisations is amalgamate, or at least affiliate, and make a national body to be the advisory council to the government on what is actually happening out there, so that our people have a voice at the highest level so that we can lobby, we can advertise and we can market to the general public if we have to, apart from our politicians, to make sure that they understand what's going on, because they certainly don't at the moment. Thank you, Madam Chair.

MS SCOTT: Thank you for coming along.

MS SCOTT: We now have Ben Lawson who's going to be presenting. Good afternoon, Ben. Thank you for coming along today. Thank you for coming a little bit earlier.

MR LAWSON: That's all right.

MS SCOTT: We're moving ahead in our schedule quite well today, so we've assigned 20 minutes to your presentation and I might ask you a question or two, but please start when you feel comfortable.

MR LAWSON: Thanks. Hopefully I won't even take the full 20 minutes. I just wanted to touch on a couple of points regarding the draft report and I must admit for the last couple of weeks I haven't had a chance to read everything, so if some of the things I do mention are covered in there I do apologise, and pull me up and say, "It's already covered. Move on."

MS SCOTT: All right.

MR LAWSON: I'm happy to do that. It's been rather hectic at work and I've been working seven days a week for the last two weeks straight, so I haven't really had much time to review this report in full. I wanted to touch on just in regard to the intersection of disability supports and equipment, primarily with employment based issues that I've discussed previously in my earlier submission, and just to touch on some of those that I think need a bit more emphasis in the report because I think the intersection is vital. The report makes mention of the fact that some of that employment support or enabling people to gain employment and maintain employment is an important part of that whole mix and I think that's worthy and is an important part.

I think generally my observation of the report is I was very impressed and I think it provides the bones of a good way to - the focus on early intervention, emphasising the positive, that kind of stuff, is vital and contrasting it with the current system, which is almost entirely negative in that sense, is a key step and that should not be understated at all. So I commend you on that. The recognition of things like voluntary social community participation I think is critical. I think that's a key stepping point. I think it's understated from a government sort of policy perspective but I think it's something that needs to be drawn out because that really is the stepping stone between the current system where people with disabilities are marginalised and treated to some extent, in some circumstances, in public like some kind of novelty or something like that. I think overcoming that is a key part of building that bigger picture that the report talks about of making people part of mainstream Australia. I think that's critical.

For myself, when I was undertaking university studies I undertook some concurrent - I was doing a three-quarter load at university when I was transitioning from school to obviously on the path to employment, but I did university studies which I over time supplemented with some voluntary work. Having things like the disability support pension through that time is really critical, and at the same time also having some modest supports was critical. That could have been enhanced in some elements but I made do with what I did.

Having that capacity to study and to then slowly build up with other skills with some voluntary work enabled me to make what I term a sort of soft, low-risk transition to work, so I think recognition of those kind of stepping stones along the way is vital, not just saying people should all move from the current system where they haven't got the capacity to participate fully in employment. There needs to be a staged approach. It's not something that can happen overnight with people. Managing things like fatigue is a massive issue, just establishing in your own mind and getting your head around what you need to do, how you can participate. If you can do that in a sense of a lower-risk voluntary type situation or through study and the like, I think that's really valuable.

I think the current report touches on employment in a number of measures, but it doesn't fully address - and I don't know whether you can - some of the carrots that might be introduced to encourage or embed employment participation in the framework. I think obviously part of that is recognition, but then moving more fully forward, one of the things which I think is important is aligning government. I think government has a risk of running off, as they're currently on the "everybody is on the welfare" crackdown bandwagon.

I don't want to comment on that either way, but there's a risk of those kind of situations actually derailing some of the - you can set up the national disability insurance system, and then if government policy changes, that could run counter or conflict with the system. So there's an inherent need to somehow try and align those, and whether there's some way of - you're saying in the report that the treasurer would be the minister responsible within government for the National Disability Insurance Scheme, but there would probably need to be some form of dialogue in there to encourage that or to ensure that policy settings were as aligned as best as possible.

MS SCOTT: Yes. I think we do cover that briefly in chapter 17, Ben.

MR LAWSON: Okay, yes.

MS SCOTT: It may not be to your total satisfaction, but we do acknowledge that there needs to be consideration that the government should consider the impact of policy changes on the NDIA and how that would impact on the sustainability of the scheme, because you don't need to change this other policy.

MR LAWSON: Okay.

MS SCOTT: Changing the other policy could impact - - -

MR LAWSON: Yes.

MS SCOTT: Obviously it would be highly desirable if the DSP didn't act to counteract or undermine what we would see as the intention of the scheme to improve, where possible, people's social and economic participation.

MR LAWSON: Yes, I think that's important, and I touched on that a little bit later in my speaking points.

MS SCOTT: Yes.

MR LAWSON: And I don't know how to describe it, whether it's ad hoc - but it's probably not quite ad hoc - but it's just the higgledy-piggledy nature of their current system, that it's sort of assembled with a whole bunch of different agencies. The disability support pension, to a certain extent, has some of that sort of cost of disability factored into it. I think obviously that is, to a certain extent, distorting some of those, that separation of the two elements. So that's probably an issue.

So the clear partitioning, I think, between income and disability support is really important, but conversely, if it's not done right then I think people have a lot to lose. So because the report is so holistic - I'm not sure whether you've touched on this in the report; I didn't pick up on it - it's not something that can, in a sense, be picked up. It's going to be difficult if government starts picking and choosing bits of this report, because it's constructed as a whole. That's always going to be a risk, I guess, and something none of us can probably guard against, but there probably needs to be some sort of statement that if they start fiddling, then they've got to really take an axe to the current system and probably change it, because otherwise we're going to end up with yet a whole other hybrid system without some of these eventualities properly considered.

You're talking about a memorandum of understanding that states and the Commonwealth - and obviously that needs to touch on things like income support and also other disability supports and about how you might progressively or at one go remove all those, change the system, but obviously there needs to be some level of cooperation - and also with the states I think - to touch on some of those issues. Because there are a lot of current disincentives in the current system, things like the state based schemes - I'm not sure what I'm quite getting at there, but - - -

MS SCOTT: I've read ahead, Ben, and let's see if I've interpreted it correctly. I think you're saying that, because some benefits at the state level depend on entitlement to things at the Commonwealth level, a change of things at the Commonwealth level could inadvertently disadvantage people at the state level.

MR LAWSON: Yes, that's true.

MS SCOTT: Have I got that right?

MR LAWSON: Yes. If the NDIA comes into existence, any future things that they might add to that on a state based level or something - it should be based, in a sense, on a stand-alone system. I think that current interlinking is hugely problematic. That's the case that I'm citing there. Really, at the moment there's a strong need for me to stay on a mobility allowance, largely because of my state based equipment and support. I've got quite a deal of medical equipment, my chair and equipment in the home, et cetera, that's very expensive, but essentially eligibility for that is contingent upon a Commonwealth support. So it's this complex interlinking. It would be good to start to break down those linkages as the scheme progresses.

Yes, the other key thing - and I'm hoping it's in there, but I haven't found it yet - is that I understand you're still at the broad, sketching-out stage of this whole system, but I think it's a bit light on detail on what sort of levels of support and how that might transition between the sort of various transition points and life factors you talk about.

MS SCOTT: All right. You want more cameos?

MR LAWSON: More cameos.

MS SCOTT: Yes.

MR LAWSON: I just even think some hypothetical examples for people, as they move through their lives, how they might consider that.

MS SCOTT: Yes.

MR LAWSON: So you talk about where they can access voluntary support in the community, et cetera. Just to tease that out would be useful, just to paint a bit of a picture how the system might be structured. You're saying there that parents might be expected to undertake reasonable assistance for a child, et cetera, in sleeping and things like that, but it's how that then plays out through the course of somebody's life, and it would be really useful, I think, just to paint a bit more of a picture as to where we're heading, to sort of sketch out that forward.

MS SCOTT: Yes.

MR LAWSON: And so that, by extension, would then touch on some of those, give people a firmer idea of the level of support they might be getting. It then would give an indication also about that pressure or the drivers for people, how much capacity people are going to have to alter their living arrangements to get some benefit from the assessment or anything like that. Obviously that's undesirable. So, yes, I think sketching that out would give people a better picture to work from.

You've made numerous mentions of the person-centred approach and I totally agree with that, but I think it also needs to be further elaborated along the lines that, where possible, that assessment should be positive and proactive, so really emphasising the fact that it's about engaging with the person and that they're not going to be disadvantaged as a result of expressing some desire to achieve something. At the moment really there's a huge amount of inbuilt penalties. I think if you were in the current crisis based system, to express desires to do things, you'd probably go to the back of the queue, which is ironic and it's the real antithesis of where we need to be.

I think part of that is also, in that discussion about needs versus wants, making clear that things like community participation and employment support are a need, not a want. I think that's part of that bigger model of and change to disability support as a whole; so to actually say that that's not just a luxury, that this is actually something where people need to be.

MS SCOTT: Yes. I'm thinking - - -

MR LAWSON: I think you've gone to that to a certain extent.

MS SCOTT: I think I've got it. I think I've got that in chapter 4, but by all means have a look and see whether you want us to just - - -

MR LAWSON: Yes. There's a fair bit of it in chapter 5, but I think it just needs to be reiterated probably.

MS SCOTT: All right.

MR LAWSON: Sorry, it might be chapter 4.

MS SCOTT: No, I think you're going to be right. I think it's going to be chapter 5.

MR LAWSON: One of the other key things which probably needs to be emphasised: the report obviously talks about reassessing people at key transition points in their life, and I think that's thoroughly appropriate. The basis of the current system is that you've got to get what you can in the first assessment, because you're going to have very little chance of going back and getting more. It would be good to tease out just a bit more about that reassessment process and, if people think their situation has deteriorated or changed in a significant way, that they can trigger a reassessment, and it might be a relatively low bar to do that, but I think just having that reassurance is the key point. It would give people more confidence that they're not going to be stranded; you know, say they've just entered university or whatever and their situation changes, that they're not going to then be stuck with that arrangement indefinitely or until some other externally applied cut-off point.

MS SCOTT: Yes. That's fine.

MR LAWSON: I think that's about it.

MS SCOTT: Okay. Thanks again.

MR LAWSON: Thank you. I think it's a great report. It's taken a bunch of economists to actually come up with a model that's far more sustainable and positive and a massive step forward, rather than, you know, a whole lot of agencies individually - or they haven't got there yet - so I think it's a credit to you for doing that.

MS SCOTT: All right. Thank you very much. I'll pass your compliments on to the team. We have got some material on community access and I might just read it to you, because I want to ask a question about the community participation. Some other people have raised it with us as well: the idea that we may have understated the role that voluntary groups can play and the importance of people either volunteering, as you did, in university days as a means of assisting the community, but also to increase your own skill sets. So we might just spend a few minutes on that then?

MR LAWSON: Yes.

MS SCOTT: Okay. We had some interesting testimony in Melbourne, Ben, where someone explained that, until they had a grandchild with a very significant disability, they didn't realise that basic therapies weren't funded by governments. It turns out - and it's well accepted clinically, apparently - that her grandchild requires certain equipment to assist in their standing and so on, but it turns out when she met the therapists they handed her a large tin to start off with the charity-raising. So at the moment we've got charity-raising for things like wheelchairs for some people, charity-raising for basic therapies, charity-raising to help people get into basic supports.

If we have a system that's well funded, what do you think should be the role of the community sector? What should be the role of Rotary and Lions and other community based organisations when it's not about providing basic supports? What role would you see them playing in a better environment?

MR LAWSON: I've always said that I think those kinds of organisations, and I think businesses as a whole, et cetera, have a huge role to play in the things that they can offer people, in giving people opportunities. I think it needs to be a genuine thing, not just another source of cheap labour or whatever, but I think community organisations are ideally placed to reach out. I think if you got those formal channels set up with things like that community outreach component of the NDIA and also obviously the different disability - I can't remember the terminology used, but disability organisations across the country - there's a huge opportunity for them to interlink with those community organisations and business to create opportunities, to mentor people.

I think mentoring is a huge thing. It's two phases. It's about upskilling people and it's also then about taking that next step of creating a sustainable and a broader base of disability leadership, I think. There are obviously some very notable Australians with disabilities. The Australian of the Year is one of them, and not necessarily the scope that is going to be covered by tier 3 in the disability support scheme, but nonetheless actually out there. It would be good to build that base much firmer and wider and, as part of that mainstreaming, I think that's vital. Obviously organisations like Rotary are well placed, especially for people that have got the scope and potential to enter the professional-type fields. I think that role is important.

I think the charity situation has got us into a whole heap of - I'm not for a moment trying to undermine or discredit the charity model, because it's important in the current system, but I think where possible we should move away from that so that people aren't viewed as charity cases or something. I don't want people to look at me and feel sorry or anything like that. I don't want that. If people try and treat me differently in the work environment because of my disability, then I'm offended by that. They can challenge my ideas all they like, I don't mind that, but I don't want to be treated differently. I think one of the problems with the charity model is that it embeds that whole situation and that's one of the problems with the current system.

MS SCOTT: Okay.

MR LAWSON: I think if we can move to that more proactive, constructive, working together type relationship then we'd be on a much more solid footing, and obviously a better-funded system is the bridge to getting there.

MS SCOTT: Okay, Ben. Thank you very much.

MR LAWSON: Thanks for the opportunity.

MS SCOTT: Thanks for coming along today, for your submissions and for your presentation.

MR LAWSON: I shall write that up in a more comprehensive and readable form.

MS SCOTT: Okay. Thank you.

MS SCOTT: I now call to the table Rod Hodgson, please. Good afternoon, Rod.

MR HODGSON (ALA): Good afternoon.

MS SCOTT: I understand you're representing the Australian Lawyers Alliance. Is that correct?

MR HODGSON (ALA): I am. May I refer to you as Patricia?

MS SCOTT: Yes, please do. We've assigned to you 30 minutes. You might allow just a little bit of time for questions. Thank you. Please proceed.

MR HODGSON (ALA): Thank you, Patricia. My understanding was that I should seek to limit my presentation to about 10 minutes and then allow maybe up to 20 for questions.

MS SCOTT: We'll see how we go.

MR HODGSON (ALA): Sure. My name is Rod Hodgson and I'm the managing partner for Maurice Blackburn Lawyers in Queensland. Maurice Blackburn, together with a couple of other major law firms, have lodged a submission prior to the draft report being produced.

MS SCOTT: That's correct, yes.

MR HODGSON (ALA): I'm a practising specialist personal injuries lawyer. I've been working with seriously and catastrophically injured people and their families for all of my career. I'm a state committee member of the Australian Lawyers Alliance and the alliance's Queensland branch welcomes you to sunny Queensland and welcomes the opportunity to participate in the public hearing.

The Australian Lawyers Alliance supports the principle of a need for increased and more effective funding for people with disabilities and welcomes that concept, but the draft report raises a number of concerning issues. Our first issue relates to the implementation of a dual NDIS and NIIS alongside one another. That raises the real risk of a duplication of roles, service delivery and administrative costs, and as I'll refer to in the context of the New Zealand scheme, administrative inefficiencies are to be avoided if at all possible.

It is imperative that any proposed scheme catch people slipping through the current cracks in the system, and to do so in an affordable and - just as importantly - sustainably affordable way, and to do so without extinguishing existing rights. In some senses I think the evolution of the debate about improved services has generated a cleft, a common law versus no-fault dichotomy. That's a false dichotomy, in my view, because in my view the evidence is clear that the schemes that work best within Australia and overseas are hybrid schemes with sensible no-fault benefits available but where access to common law, with no or minimal restrictions, is retained and encouraged.

The themes of self-determination and empowerment are at the heart of many or most of the submissions from entities representing disabled people. It's the alliance's view that the abolition or curtailment of common law rights is anathema to self-determination and empowerment. The reduction or extinguishment of common law rights often heralds lowest common denominator outcomes. The common law has proven itself to be a resilient and flexible vehicle for allowing people to get on with their lives with less bureaucratic interference, and it's accordingly the alliance's view that any scheme which removes existing rights, as distinct from adding to them, ought to be fundamentally opposed.

In the case of the draft report recommendations to abolish or restrict common law rights in respect of care, where they're based on myth, supposition or a poor understanding of the functions of the common law system, those problems in the draft report must be challenged. In that regard the report says that there is no structured process or consistency across individuals. That's plainly wrong. The common law system has evolved over hundreds of years and its structures and processes underpinned in many hybrid schemes by some no-fault benefits do ensure consistency but they also recognise that, just as many disabilities differ in their manifestations, so too were claimants' circumstances different pre-disability. The word "lottery" is used in the draft report. That's a very unfair descriptor.

The draft report's criticism of common law schemes on the basis of the period of time cases take to resolve is misguided. In my experience the vast majority of cases resolve inside two years. The statistics are similar across this country but, just for Queensland, 95 per cent of District Court civil matters resolve within two years of their commencement and in the Supreme Court 99.2 per cent of civil matters resolve in the first 12 months of their commencement. In the last decade, on top of those statistics, pre court proceedings requirements have been mandated in most states of Australia and, in many cases, cases resolve very quickly without even the need for the filing of court proceedings and the entry into those statistics that I mentioned a moment ago.

It is implied within the components of the report dealing with common law that most common law settlements are small and may inevitably run out. The corollary of that view is that people are better off without common law and on a long-term drip-feed. Again, I would say that's a myth. In our experience well-managed damages settlements for serious and catastrophic injuries make a profound lifetime difference to care, aids and equipment provided to our clients and are invariably superior to the minimalist offerings of solely no-fault schemes.

So if the common law has a 500-year track record in dealing with the effects of serious disability and adapting to new challenges our world throws at us, the evidence on the simplistic "throw the common law out the window" model is strongly against the efficacy of those schemes. They don't work. They don't work because they become unaffordable and as soon as they become unaffordable the architects of those schemes, or the administrators, do the very opposite of what was originally intended to be achieved and they screw the benefits down to parsimonious and demeaning levels.

We only have to look across the Tasman to New Zealand. The draft report, with respect, did not take a clear enough microscope to that system. Some 40 years ago New Zealand threw common law rights out and implemented their ACC scheme. It was a disaster almost from inception and has gone from bad to worse. Firstly, despite advances in safety technology, the New Zealand experience has not effected any increased safety records. The opposite seems to be the case. The deterrent effect which the draft report of the Productivity Commission challenges, but which lawyers who work in this area strongly believe in, has gone.

Secondly, almost from inception the New Zealand scheme has had multi-billion-dollar unfunded liabilities. In a nation with less people than Melbourne, the present unfunded liability has grown in the last four years from $NZ4.2 billion to $NZ12.7 billion, predominantly through inadequate levies and having spawned a huge and inefficient bureaucracy. The 2009 annual report of the ACC noted that the scheme was unsustainable at that rate of loss and the 2010 financial condition report raised solvency crises and said that a $NZ17 billion injection was needed to meet commercial solvency criteria. But, most importantly and most tragically, the legislative response to funding difficulties has not been to say, "We've got a fundamentally flawed system here," but instead to screw down the benefits to those who were intended to benefit when the scheme was dreamt up.

Here in Australia we would invite the Productivity Commission to look more closely at some of our state and territory schemes. The evidence, in my submission, clearly shows that the retention of common law within a hybrid scheme is a fundamental driver for finality, smaller bureaucracies, self-determination and empowerment of disabled people and therefore affordable funding for such schemes. The South Australian workers compensation scheme is a case in point. Over a decade ago South Australia, for work-related injuries, abolished the right to bring common law damages claims. That scheme, like New Zealand's, is a debacle. It's now, in that low-population state, over $1 billion in the red, with a statutory no-fault scheme, with benefits having been screwed down and no-one being entitled to be treated the way they were at common law.

Contrast that with here in Queensland. Queensland has effectively unfettered access to common law damages for injured workers. It has statutory no-fault benefits available, in terms of weekly payments of compensation, medical expenses and statutory lump sums. The Queensland bureaucracy is smaller and, crucially, in the affordability and sustainability sense, the premiums to employers are around one-third of South Australia's. There are other examples in Australia.

Many observers of jurisdictions outside Australia consider that the United Kingdom generally does better than Australia in long-term care for the disabled. The Four Corners program, which was about 18 months ago, when this issue first came onto the political radar in a more defined way, paid a lot of attention to the UK scheme. The draft report pays little attention to the UK. The benign view is that that didn't occur through a shortage of time. Another view is that scrutiny on the UK would unequivocally support the benefits of common law as a key component of care for seriously and catastrophically injured people. The United Kingdom has for a long time had a robust and healthy common law system.

Notwithstanding the draft report's attack on the benefits of common law, people who work at the coalface say that common law has an important role to play in risk management; that is, the deterrence of negligent conduct. It would be offensive in our view for a person who has suffered a serious injury as a result of the wrongdoing of another person not to be able to pursue damages for all their losses, including long-term care.

The Australian Lawyers Alliance sees common law as a fundamental component of any scheme, hybrid in its nature, with no-fault benefits as a safety net aligned with common law options. Whether it's an opt-in or an opt-out model, the funding interrelationship between a no-fault and common law scheme are imminently manageable. We already have in Australia long-term models for sensible payback and preclusion arrangements, both under the Medicare and Centrelink schemes.

The final point I want to make is about affordability and sustainability. Whilst it is accepted that the costing of the scheme is at a primary stage, it seems to be founded on an assumption that the number of beneficiaries and average costed benefits can be accurately gleaned from existing Australian stats. We have great concerns at the proposed level of funding. The draft report seems to average the cost of care at approximately $1 million for the lifetime of each catastrophically injured person. That seems to us to be a woefully inadequate sum, and if matters were to proceed on anything like that premise, we will, as night follows day, see the New Zealand experience of legislative or bureaucratic restriction on the type or cost of services available to participants.

By way of example of the rubberiness of those figures, the draft report notes the discrepancies between the two separate sets of statistics, the burden of disease statistics, and the 2009 Survey of Disability, Ageing and Carers. This lack of statistical clarity at this point supports the fragility of a scheme introduced without further careful cost modelling, and the risk of cost burdens for future generations of chronic underfunding in its formative stages, like New Zealand, with the consequences of that most likely being the chainsaw being taken to entitlements.

So a detailed costing of the proposed scheme, based on sound assumptions and not guesswork, must occur, otherwise it will be impossible to predict the overall cost of the scheme and, hence, the ambit and quality of the services to be delivered on a sustainable basis. Those uncertainties in funding, with a common-law-abolished structure, need to be contrasted against the long-term successes of hybrid models with common law rights maintained and protected.

MS SCOTT: Thank you. We might not have time to discuss each of these key points that you've raised, but I wouldn't mind if we could get the assistance of the Australian Lawyers Alliance, to come back with maybe some responses to questions, for example.

MR HODGSON (ALA): We'd be happy to.

MS SCOTT: On page 2 of your presentation you've provided some estimates on resolution of cases within two years, and then the figures. You've got some Queensland statistics there. It would be great to get as many references as we can. You say, later on, "Many cases resolve quickly as a consequence." If you could document what lies behind the reference "many" that would be very useful.

MR HODGSON (ALA): I'm happy to talk to that issue now, if you would like me to?

MS SCOTT: That's fine, but I've got a few that I want to go through. I'm actually after references. If you could cite references for me that would be useful. You thought the "lottery" description was unfair. I'm just going to take it on the basis that your presentation there of our report is accurate. What proportion of cases do you think, in your practice, would probably reach settlement rather than going to court?

MR HODGSON (ALA): Over 98 per cent.

MS SCOTT: Okay. To what extent would it be the case that while there's 500 years of - have I got that right? I think you used 500 years, didn't you, Rod?

MR HODGSON (ALA): Yes.

MS SCOTT: So while there's 500 years of common law - now, what's the next word you'd like me to use: "common law system" or "common law outcomes"?

MR HODGSON (ALA): Evolution.

MS SCOTT: Evolution. If 98 per cent of cases are actually the result of settlement, what's your response to the contention that that depends then on, obviously, the quality of the lawyer, the resolve of the person, the nervousness of the person either side to - in the case of the insurer - reach an outcome? In what sense isn't it a lottery, when there are so many variables? It's not as though you're going to a benchmark or an independent assessment in that case.

MR HODGSON (ALA): Yes, the cases are benchmarked by precedence. Similar cases have been dealt with in the courts, progressively, over tens of years, in some cases over 100 years. So there are strong indicators of the way a current case will be dealt with by reference to the way previous cases have been dealt with. Both the defendant - that is, the person who has to pay, usually supported by an insurer but not always - and the plaintiff can perceive their case within that sort of historical framework. Every case is different on its facts, and the ones that end up going to court normally end up being the ones that are very contentious, either as to a dispute on the facts or a dispute about the medical material. I emphasise again that the very high majority - it's in the high 90 per cents - resolve, usually amicably, after a process that is not nearly as lengthy as parts of the report would suggest.

MS SCOTT: But you must have clients that have high expectations, and you must have clients that have low expectations, you must have clients that are nervous and other clients that are assertive. To what extent does that have a bearing on the outcomes and the settlements delivered?

MR HODGSON (ALA): "Yes" to all of those personality differences, and good lawyers can read those personality aspects and provide reassurance that the merits of that person's case and the pros and cons of that person's case have been taken into account and will be assessed, if necessary, in that tiny proportion that go to court, by a court.

MS SCOTT: But if you actually had a combination of an assertive or resistant insurer, not a good lawyer, and a nervous client seeking damages, you don't think that then reflects a certain lottery outcome relative to someone that had, for example, a great lawyer, a passive insurance firm and an assertive person seeking claims?

MR HODGSON (ALA): Those dynamics are all relevant but I don't think they're central. There's been a centralisation of the operation of plaintiff personal injury law firms in Australia over the last 15 or so years. Most lawyers, if not themselves then with the assistance of counsel, do a pretty good job at assessing the merits of a claim and a pretty good job in saying to an insurer, if the insurer is being difficult, to take a bit of a flying jump and push the case further to where a reasonable outcome is then achieved for the client.

MS SCOTT: Okay. Thanks for that. In relation to the ACC scheme, we actually have had a look at the ACC scheme and quite a bit of the report refers to the experience of the New Zealand scheme, including recent issues. But I am interested in your comments about benefits being "screwed down to parsimonious and demeaning levels". Could you provide material on that, please; the evidence?

MR HODGSON (ALA): Yes, happy to do that by way of comparing and contrasting what similar cases would achieve under Australian common law and statutory jurisdictions.

MS SCOTT: The bits I'm particularly interested in are where you say "benefits are screwed down to parsimonious and demeaning levels". So I'm interested in you providing material on how the New Zealand scheme has moved from where you thought they were before down to where you now see them as "parsimonious and demeaning levels".

MR HODGSON (ALA): Sure, happy to.

MS SCOTT: If you could also provide comparable figures for Australia, I'd welcome that.

MR HODGSON (ALA): I should add that that has occurred incrementally but significantly. That scheme is 40 years old.

MS SCOTT: Yes.

MR HODGSON (ALA): I see that the draft report observes that the problems with that scheme are about it not being governed properly or managed properly. My response to that is that that scheme has been in existence for 40 years across governments of both conservative and more progressive approaches under multiple ministers, and it's far less about governance than the genesis of that scheme. It is fundamentally flawed, in our submission. But, yes, I'm more than happy to provide comment on the levels and compare and contrast.

MS SCOTT: All right. I am intrigued about why a system like that that's just so - using your words - clearly flawed can survive for 40 years. You've said successive governments of either persuasion have retained it. Can you give some observation about why that would happen.

MR HODGSON (ALA): It's a conundrum.

MS SCOTT: It is a conundrum.

MR HODGSON (ALA): "Survival" is probably not the right word because it has subsisted and it has subsisted on the basis of being funded by the taxpayer and it continues to have - across each of its components there are separate funds for motor vehicle, workers and so on.

MS SCOTT: Yes.

MR HODGSON (ALA): Some of them are only about 30-something per cent funded as we speak at the moment. So it really should have had something done to it a long time ago and "survival" is probably not the right word. It's not survived; it's there.

MS SCOTT: All right. I'd be interested in your view about the 40-year conundrum. That would be good. You comment on New Zealand's safety record. Any material you've got on that, I'd welcome that as well. I think you made reference to the Four Corners program. I do recall that. If you could give me the references in that program to the common law system in the UK, I'd welcome that as well.

MR HODGSON (ALA): The point about the Four Corners program wasn't that it expressly articulated what the components of the common law system were in the UK. It's that that program highlighted how well, by way of contrast to Australia, the disability services were delivered, and my point is that that occurs within a robust common law system is a positive and it's consistent with the ability to have a hybrid scheme that maintains common law and delivers those services.

MS SCOTT: Okay. So you're saying that program didn't deal with the UK common law system?

MR HODGSON (ALA): By implication it did; not expressly.

MS SCOTT: Right.

MR HODGSON (ALA): But I'm happy to give you the reference and provide more detail - - -

MS SCOTT: No, I remember the program. I couldn't remember it dealing with the UK common law system. That's why I wanted you to check whether that was your recollection as well.

MR HODGSON (ALA): Sure.

MS SCOTT: All right. Thank you very much, Rod.

MS SCOTT: While we're waiting for someone to come, is there anyone in the floor that would like to speak that hasn't had an opportunity yet? Welcome to the table, Cosette. Would you state your name for the record, and I understand you've been witnessing the hearings and wish to make some comments, so maybe you could contain your comments to five minutes or so.

MS URBANI: Yes, not a problem. My name is Cosette Urbani. I actually work for a service provider within Queensland. However, I've just come along as an observer today and I'd just like to make a few comments for the record.

MS SCOTT: That's fine, thank you.

MS URBANI: First of all, there are about five that I want to quickly cover, but they're mostly statements, so there's not going to be too much in it. Education and training: I believe that if we do actually put funds into young people with disabilities, we can then lessen the burden as they get older because they will then be able to provide for themselves, whether it be in a small or a great way. We've seen people who have disabilities who go to college, with a little bit of assistance. Then have gone on to achieve great things.

I'd just like to tell you an experience of my niece. She's not working. However, with a little bit of funding, a little bit of education, she does go to a respite service and she doesn't like conflict, so whenever there's a conflict in the centre she's put right in the middle of it because within five minutes that conflict has settled down.

MS SCOTT: Right.

MS URBANI: She just has that really, really calming effect on people around her, so they actually utilise her services. She actually sort of signals that she wants to get over there and do something about the conflict. It could just be somebody who's being a little bit loud and she just wants to make sure that they're okay. So, yes, that's part of the education and training.

MS SCOTT: Yes.

MS URBANI: I do have a concern with the way packages are distributed currently and will be in the future. I've seen a lot of mismanagement of funds and I've also seen care providers not actually providing the services, as outlined earlier on. I just want to echo Lillian's views that if the packages were self-managed, then they can actually get the right people in to do the jobs for that current situation. She is also right about trying to get family to take on board the responsibilities of being a carer.

In my experience I've been to many people's places who have said, "I can't get a carer. I don't have family. When I advertise for a carer they come in and they use me," or, "I don't like to ask them to go and clean my toilet or behind my toilet, because it smells, because that's not a very nice job," and I try to get through to them that it is actually their job, that they are coming to clean or coming to specifically do duties, and they're actually doing themselves a disservice by trying to be nice to the person who's coming in to do those services.

MS SCOTT: Yes.

MS URBANI: I also believe that part of the role of the service provider - let's take cleaning for an example. If they're not able to do a specific task - like dust the ornaments on the television, in case they knock one off and break it, so that then becomes responsibility of the caree - maybe they can give a bit of training or a little bit of help about how they can actually do these tasks for themselves for their current ability.

MS SCOTT: Yes.

MS URBANI: In my observations this isn't happening. It's just like, "We've just come here to do this, so that's all we're going to do." But we all know that if you're taught to put on your own socks, then you don't need someone to do that for you. I don't know whether that's a fear of maybe losing their position and losing that financial side of things, but it then opens the floor up to other tasks that they're able to do.

MS SCOTT: Okay.

MS URBANI: Community organisations can play a huge part in the education and mentoring roles. I know that was brought up by Ben just recently, and I thought he answered the question really well about what Lions and Rotary people would do. One of my positions is actually at a community centre, so we see what we would do with the money if we didn't have to provide this service, that we could actually tackle other things, and where we are placing our funds that aren't going on having to pay somebody to do the menial stuff and that, that these packages would cater for, is that we are doing mentoring and early intervention training.

MS SCOTT: Right.

MS URBANI: For example - and this is an example we're doing at the moment - we're working with the Lions Club and we're working with people disadvantaged. They could have some disabilities, as in intellectual disabilities, and may not be able to feed their children properly and provide the clean environment and things like that. So we actually have a group of Lions people who we match with the general community and they go out and they mentor them.

MS SCOTT: Yes.

MS URBANI: It's cutting down on the drain of a service provider having to go out there. That's what I would see the Lions, Rotary and that sort of thing coming along in the future.

MS SCOTT: How is that working?

MS URBANI: It's a ripper. It really is. It's working really well. We only target three or four families at a time and it's usually six to 10 weeks. In our current community as well, we've also got the St Vincent de Paul, who have started a mentoring program which we can tap into as well. So we can get a little bit of their expertise and we share our expertise. People with disabilities can actually play a part in that by offering their expertise.

MS SCOTT: Yes. They can be a volunteer as well.

MS URBANI: For example, the Amputees and Family Support Group - sometimes it's easier for an amputee to go along and show another amputee how to do things and what to do. That's where a person with a disability can then share their experience and knowledge with another person with a disability; therefore, again, breaking down the amount of money that needs to be spent on training a particular task.

MS SCOTT: Okay, are we up to point number 4?

MS URBANI: That was point number 4.

MS SCOTT: Good.

MS URBANI: Sorry.

MS SCOTT: That's all right. No, you're doing well.

MS URBANI: I think this was raised by Francis yesterday, but I did actually want to make a point about alterations of vehicles. I believe she said that there should be maybe a one-off case of funding so that we can actually have vehicles modified and have ramps put in place and be able to get that better wheelchair - because there is always a gap. Currently, if an amputee leaves the hospital and needs to have home renovations in their own home - it's a bit different if it's in a Housing Commission place - they can access funding from HACC, which allows them the workmen and then to actually build, say, for example, the ramp. However, the materials must be purchased by the other person. So a $4000 ramp could still cost a person $1500 to

$2500, depending on how big it is and what needs to be done. Bathroom renovations are another huge thing. Yes, they will provide the person to come along and put the handrails and that in; however, you still have to purchase those handrails yourself.

MS SCOTT: Yes.

MS URBANI: And because they're not part of a package, that causes a financial strain.

MS SCOTT: Yes, I got that.

MS URBANI: I would like to see - and echo, again, Francis saying maybe with the modifications of the vehicles and that, that is just so expensive.

MS SCOTT: They are. I'm almost loath to mention New Zealand after the last speaker, but I think I will anyway. But it was interesting that in the New Zealand experience they actually looked at, Cosette, the cost of providing an attendant and a modified taxi - to allow people to access doctors' appointments and normal things, shopping and going out once a week or whatever - and they then compared that to the cost of vehicle modifications and the cost of training people to use modified vehicles.

MS URBANI: Yes.

MS SCOTT: And in some cases - not in all cases, but in some cases - it actually can be cheaper to provide people with independence - - -

MS URBANI: Absolutely.

MS SCOTT: - - - through vehicle modification than it is to provide subsidised taxis. So actually in the report, on page 21, we do suggest that vehicle modifications would be included.

MS URBANI: Yahoo. Sorry, I'm so excited.

MS SCOTT: But, of course, subject to assessments and so on.

MS URBANI: Yes.

MS SCOTT: So that's something that we have - - -

MS URBANI: I would actually like to see it obviously nationally, and have the same benefits for people that are coming out of the hospitals and then the after-care services all be across the board, because at the moment it's a bit higgledy-piggledy.

MS SCOTT: Yes, okay.

MS URBANI: My final one - and I don't know if this is the place to actually bring it up, but - - -

MS SCOTT: What the heck.

MS URBANI: It brings it up with education and training, that our prosthetists who are actually supplying and make the limbs up in Queensland, they're getting on a bit.

MS SCOTT: Yes.

MS URBANI: And we've been pushing the barrow about addressing the issue of ageing prosthetists for a long time.

MS SCOTT: Yes.

MS URBANI: And we were hoping that we could maybe look into some sort of an avenue where - I suppose it could be likened to an apprenticeship, because at the moment they come out of the universities and they have minimum hands-on experience working with people. They've had hands-on experience working with the equipment and the materials, but not matching them up. So it would be nice if we are able to actually get a little bit of extra funding for the prosthetists to take on board these people and train them properly, without having to - you know, it takes a lot out of their finances and their money as well. That was my last thing that I wanted to bring up.

MS SCOTT: Okay. You're not the only person that's raised it, so thank you for doing that, because it reminds us that there is an issue there.

MS URBANI: Great. Thanks.

MS SCOTT: We now have Queensland Advocacy Inc, please. Good afternoon. You're our last customer for the day, so I should say that you've got 30 minutes, but if you feel you'd like to take 25 minutes, that would be great.

MR WADE (QAI): Okay.

MS SCOTT: But anyway, you're most welcome. Would you like to identify yourself for the record. I know you're representing Queensland Advocacy Inc. Please start when you feel comfortable.

MR WADE (QAI): My name is Ken Wade. I'm the director of Queensland Advocacy Inc.

MS BRADSHAW (QAI): My name is Rebekah Bradshaw. I'm a systems advocate at Queensland Advocacy.

MS SCOTT: Sorry, I didn't catch that. You're the?

MS BRADSHAW (QAI): Systems advocate.

MS SCOTT: Systems advocate?

MS BRADSHAW (QAI): Yes, one of a number.

MS SCOTT: Good. Thank you.

MR WADE (QAI): Before I start, I'll just say that I have a vision impairment, so it's very difficult for me to try to use notes when I'm doing a presentation, and because we made such a hasty decision to appear before the commission, I haven't had time to fully memorise the notes I was going to use, so I have them here on what's called Victor Reader. It's a special device, something like an MP3 player, but for people with vision impairment.

MS SCOTT: Okay.

MR WADE (QAI): So if I sound a bit slow or if I seem to stop oddly on occasions, that will be why. It's because of the way the speech synthesis is working.

MS SCOTT: That's fine. Take your time.

MR WADE (QAI): Thank you for giving me the opportunity to speak here today. It was only yesterday that I found out I would be appearing here. Consequently, my submission is brief and, I am sure, ill prepared compared with those you've already heard and will hear after me. Further, it is limited to only one subject: the role of advocacy under the NDIS. As I already said, I represent Queensland Advocacy Inc, a small community based systems and legal advocacy organisation for the most vulnerable people with disability in Queensland.

"Advocacy" can be defined in many ways. For us, it means speaking, acting and writing with minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person or group to promote, protect and defend their welfare and justice by being on their side and no-one else's, being primarily concerned with their fundamental needs, remaining loyal and accountable to them in a way that is emphatic and vigorous and which is or is likely to be costly to the advocate or advocacy group.

Why do people with disability need advocacy services? For the same reason we need a police force and judicial system: because there are always people who try to take advantage. Many people who try to take advantage don't even realise that is what they are doing, particularly when they are trying to take advantage of someone who has a disability. It has been this way ever since the first time a child born with disability was exposed on a hillside to die.

It continues to be this way because the prejudice continues. The prejudice continues because there are still many people who don't see a whole person when they see someone with a disability and, because they see someone who is less than human, they see someone who feels less deeply than they do or who needs less powerfully than they do. They see someone who should be content with less: less money, less advantage, less opportunity, less control over their own lives.

These attitudes are chronic and widespread. They do not uproot themselves. They fight vigorously and unstintingly for their survival. They are persistent and pernicious. My most earnest wish is that the NDIS will constitute the stakes through the heart that will finally put to rest this ancient curse. My greatest fear is that the NDIA will become infected by it and will become one more facet of the problem rather than a part of the solution.

Advocacy is a fundamental safeguard against the prejudice that daily threatens the rights and fundamental freedoms of people with disability. To be effective, it must be independent of the entities which are likely to be the subject of its focus. Incorporating advocacy services into the entities which are likely to be the subject of its scrutiny creates not merely a perceived conflict of interest but an actual one that cannot be condoned. The divided loyalties involved would inevitably be resolved in the entity's favour.

The commission must constantly recall that people with disability are among the most vulnerable, disadvantaged and easily exploited groups in society. Many lack the resources, knowledge, communication skills and capacity to advocate for themselves. They need the support of advocacy organisations to help them understand and enforce their rights. They are entitled to this support under the Convention on the Rights of Persons with Disabilities and the Disability Services Act 2006, Queensland.

One of the principal tenets underlying the commission's own report is the need to increase equity, choice and self-determination for people with disability. This means the range of advocacy supports available to people with disability must increase under the NDIS without in any way diminishing the quality or dividing the loyalty of those supports. All forms of advocacy, including paid advocacy, must increase under the NDIS to meet the increased standards of equity and choice mandated under the proposed scheme.

Funding for paid advocacy may legitimately form part of the NDIS, but provision of those services must be sourced from organisations entirely independent of the NDIS or any other entities that might reasonably constitute the focus of that advocacy. Further, the funds to support advocacy must not be drawn individually or collectively from the funds allocated for a person's support needs. They should be drawn from a separate budget allocation or from the general pool of undisbursed capital, what might constitute within the NDIS the equivalent of consolidated revenue. That's the end of my formal presentation.

MS SCOTT: Thank you very much, Ken. That was very clear and well presented and, given that you only had a day's notice, I commend you on the quality of it.

MR WADE (QAI):   Thank you.

MS SCOTT: I think I've got your basic point, which is that while you're supportive of the proposal in the draft report, you strongly recommend to the commission that we consider that there be funding for advocacy and that it shouldn't be drawn from a person's individual package. Have I got those two key points?

MR WADE (QAI):   Yes.

MS SCOTT: Okay. Well, I've got that.

MR WADE (QAI):   And that it also needs to be independent of the NDIS or any other entities which are involved in service provision or which would likely form the subject of scrutiny by the advocacy agency.

MS SCOTT: All right. I might then return to that third point. Ken, it's good that we've got this process, because sometimes you think you've done a job and you write it a certain way and, lo and behold, people can't see it there or they think you're on the wrong wavelength or taking the wrong approach.

We were very conscious that we can be dealing with people who are vulnerable and disadvantaged and potentially easily exploited, and that's why we have got this "disability service organisations" now - maybe it's something in a name, but I just want to explore it a little bit more with you - which would be available to people and that would basically stand in their corner when the assessment process was occurring and when it was being finalised; would stand in their corner if a person had trouble with an actual service provider; if they found that their attendant care person wasn't turning up or they found that the cleaning service was inadequate; they found that the cinema didn't have easy access - whatever. There would always be someone that they could call on and this would be, if they wished it to be, their disability service organisation.

So they're not a service provider. They're a personal advocacy service. We thought people would want them certainly for the first initial years. Some people would want them for the first initial years of a new scheme. They might want them indefinitely. We thought it was reasonable for those people to be funded out of a person's package and that they could do some advocacy for a person. If we had those that service and we had separate funding for generic advocacy, would that meet your view?

MR WADE (QAI): What are the other roles that the disability service organisations would be filling?

MS SCOTT: For example, if a person doesn't want to manage their own package, the disability service organisation could act as the broker and say, "Okay, Fred, what are you interested in? Right, okay, these are the things you want. When would you like the attendant carer to come? Right. What sort of person are you after, young or old? Are you after a woman or a man? What sort of services are you after? What sort of interests do you want to pursue? What community access do you want? Should we arrange for you to have some training for a particular area you're interested in pursuing employment-wise?" We envisage that they could be a broker/advocate but I appreciate the need for general advocacy. Would the combined model meet your concerns?

MR WADE (QAI): Again, it's not totally independent because the brokerage service might be one of the very things that requires scrutiny because there may be some shady or suspect way in which the brokerage services are being provided. We can't support any position that would have somebody who is essentially providing services to people with disability, then being responsible for scrutinising their own conduct and activity.

MS SCOTT: Okay, fair enough. But, Ken, if you had a generic advocacy service - let's just pretend that we use your name - and Queensland Advocacy Inc still existed, got funding and so on, and you had a disability service organisation assisting someone, if someone didn't like their broker, thought their broker had cheated them, they could still bring their complaint to you but you'd have to be a hell of a large organisation to deal with 360,000 assessments around Australia.

MR WADE (QAI): Yes.

MS SCOTT: Would that be a model that you think would be all right; a dual model where there's disability service organisations very much working with individuals one-on-one, often helping them with what will be an unfamiliar arrangement, often where there have been very passive - you know, "It's this block funding or no funding." "It's your two hours of cleaning: we don't really clean but we maintain" - but still the provision of independent advocacy for people who have got generic complaints or people who have a complaint about their broker or don't feel satisfied with the advocacy of their broker. Would that be all right?

MR WADE (QAI): Yes, it would be all right but some of the people that the broker is providing services for may not be able to complain on their own without the support of an advocacy organisation.

MS SCOTT: That's right.

MR WADE (QAI): This is one of the problems. But a dual model - certainly if there was sufficient funding provided for independent advocacy services, then that is something we could certainly look at and consider in our written submission.

MS SCOTT: Okay, all right. I'd be interested in you taking that on board. Now I've got a hard question for you.

MR WADE (QAI): Do you want to take this one, Rebekah?

MS BRADSHAW (QAI): I was going to say something more, a bit, about brokerage services and their role, and not really clearly understanding exactly, I guess, or being able to envision what that role exactly would look like on a day-to-day level.

MS SCOTT: Sure.

MS BRADSHAW (QAI): But in terms of advocacy and the individual advocacy organisations that exist in Queensland, they are definitely more than providing simply an information or referral pathway or assistance to a person with disability. A lot of advocacy organisations seek out those people who don't have the capacity to even find them, so the vulnerability may be so significant that it exists because of the system that surrounds them or because they have been placed in an institutional care arrangement for a long period of time, perhaps because they have limited family involvement or no access to family. Perhaps they're from a non-English-speaking background or they're migrants who have moved to Australia and have very limited family or no family involvement at all.

I guess, yes, we would want to be clear that individual advocacy and advocacy in general is about more than just providing information to people with disability about their rights, that the rights may be there and there may be also complaint and dispute mechanisms that are part of the NDIS, and we definitely would applaud the draft report's inclusion of independent complaints mechanisms, but that advocacy also forms a part of that safeguard, if you like.

MS SCOTT: Yes.

MS BRADSHAW (QAI): And I guess we haven't thought through it exactly but would definitely put it in our submission and I'm sure that DANA, the disability advocacy organisation nationally, will have done some thinking through of that as well.

MS SCOTT: That's good. Thanks, Rebekah. Now here's the hard question. You reminded me that Queensland has a convention, right.

MR WADE (QAI): No, the Convention on the Rights of Persons with Disabilities was - - -

MS SCOTT: But Queensland has signed up to effectively that convention, right?

MR WADE (QAI): Australia has.

MS SCOTT: Yes, Australia has, but effectively Queensland - - -

MR WADE (QAI): And in so doing they've signed up all the states, all the governments.

MS SCOTT: Right, and the Queensland government haven't resiled from that, have they?

MR WADE (QAI): Not as far as I know.

MS SCOTT: Okay. We had someone giving us evidence today that was saying that she's a person that - well, I'll encourage you to look at the testimony today, Rebekah and Ken, and I'd be interested in learning your reactions, but I want to do - the person presenting earlier today pointed out that even though she needs assistance with continence aids, the lack of provision of funded services means that she can be in the position that she doesn't get more than two showers a week and that she can certainly go 24 hours without assistance that she considers that she requires. Now, would this be something your agency - a case like that, would that be something your agency would normally be interested in pursuing as an advocacy agency?

MR WADE (QAI): We would be interested in the sense that we are a systemic advocacy agency and those sorts of issues are the sorts of things that we might address on a systemic basis, but we don't have any individual advocates that would take up that particular issue. I believe there are advocacy organisations, such as SUFY, who specialise in providing individual non-legal advocacy for people with disability, and that's the sort of issues that they would be interested in.

MS SCOTT: I'm interested, given your role in the generic area, about what provisions there are for someone to take advocacy action, given the convention. Days after days, people have referred the convention to me, and I'm thinking, "Isn't that marvellous? We have a convention." And then I'm contrasting that to the fact that people then present and say they're not getting what they consider to be basic services.

MR WADE (QAI): Yes.

MS SCOTT: I'm interested in how it can be that, even though we have advocacy agencies, even though we have a convention, we don't get resolution on something as basic as someone not receiving assistance who is incontinent? How would you address that?

MR WADE (QAI): That is a difficult question.

MS SCOTT: Yes, well, that's why - - -

MR WADE (QAI): The answer would be multifaceted. While Australia ratified the convention, it hasn't been adopted into Australian law. Until Australian law actively adopts and promotes the freedoms and rights in the convention, they are difficult to enforce. They have no more than a persuasive value.

MS SCOTT: How persuasive are they, if we don't have services - - -

MR WADE (QAI): Clearly not persuasive enough. There is always an issue raised about resources: "We don't have the resources to do this." These are issues that we fight against constantly. It's a very difficult thing to move a culture that has been entrenched over many, many years. A difficulty that we face in Queensland now is that we've had the recent floods, and government has made it quite clear that the vast bulk of available resources are going to be devoted towards the reconstruction. So that means other issues take a back seat. If people aren't receiving these basic services, I suggest the people that question should really be put to are the people who should be providing the services.

MS SCOTT: Yes, that's true. Undoubtedly that's the case. I guess I've got the advantage of having an advocacy group in front of me today who are seeking ongoing funding, and I'm trying to work out where generic funding and generic advocacy ends and - - -

MR WADE (QAI): I can give you one example of generic advocacy. The government recently developed legislation called the Forensic Disability Act or Forensic Disability Bill. That came out of a report done by Justice William Carter in 2006 about the use of restrictive practices in Queensland. One of the practices that he found most objectionable was that people with an intellectual disability, who are on a forensic order that requires detention, are being kept in mental health facilities, which are completely inappropriate for people with intellectual disability because they are two entirely different conditions that require different sorts of support. He recommended that a new service be established to support these people that was completely independent of the Mental Health Service.

When the government released the first draft of the bill it was almost a carbon copy of the Mental Health Act. So apart from a few minor changes, such as the term "patient" being switched to "client", "treatment" being switched to "support" or "care", the legislation was exactly the same. So what in effect it would have done was re-created the Mental Health Department or the Mental Health Service in miniature.

When we saw the nature of the bill, we campaigned very vigorously on that basis and told the government that we couldn't give any support to the bill in that form and that it had to be taken back and completely redrafted. To the immense credit of the minister at the time, she did take it back and substantially redrafted the piece of legislation. So that's something. That's a piece of systemic advocacy that had significant effect just in the last few months.

MS SCOTT: All right. That's a good example. Ken, Rebekah, I've finished my questions. Any last 30-second words?

MR WADE (QAI): Not from me, no. Perhaps from Rebekah?

MS BRADSHAW (QAI): I don't even want to attempt to, I guess, answer your question about the young lady that provided evidence. I'm happy to go back and look at the transcript from today.

MS SCOTT: I'd certainly encourage you to have a look at the transcript.

MS BRADSHAW (QAI): Yes.

MS SCOTT: Maybe advocacy organisations get together and talk to each other about just how well things are going or not well going - anyway, I just draw it to your attention.

MS BRADSHAW (QAI): Yes. I think probably a couple of issues that may go to the heart - and I don't know because I don't, obviously, have any understanding of this woman's situation. Advocacy services make up in Queensland probably less than 1 per cent - I'm not even sure if it's that - of the Disability Services budget. A lot of them are funded through Disability Services or through FaHCSIA nationally, as we are. I guess, when you think about how little funding they would receive in the whole scheme of the disability service system as well, there are always funding constraints. Small advocacy organisations are then forced to make decisions about who they can provide support to and who they can't, and how they target that very limited sort of funding.

MS SCOTT: Yes, that's a good point.

MR WADE (QAI): Just on that issue of funding as well, the funding loses value in real terms every year because the funding doesn't increase but the need increases, yet the resources that are available to be able to meet that need grow smaller and smaller each year. So advocacy organisations actively have to wind back the amount of work that they're doing because, in real terms, the money that they're receiving is worth less and less each year.

MS SCOTT: Thank you very much. Rebekah, thanks for that point, and thank you for coming along this afternoon. With that, I now draw our hearings in Brisbane to a close. Thank you for attending and for contributing in all the ways you did, and for very attentively listening in. Thank you very much.

AT 3.48 PM THE INQUIRY WAS ADJOURNED UNTIL
WEDNESDAY, 13 APRIL 2011