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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 MELBOURNE ON WEDNESDAY, 6 APRIL 2011, AT 9.01 AM

Continued from 5/4/11

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MS SCOTT: Good morning. Today is our third day of hearings following the completion of our draft report, and we're making a transcript of the recording today, so I'd remind our speakers that a recording is being made and will be available on the web site. While you're not required to make an oath, the act requires that your remarks are truthful. I will need to adhere very much to the time line today, otherwise we will have problems with giving an opportunity to all speakers to speak. I welcome to the table Scope and we have assigned 30 minutes for your presentation. John Walsh will be joining us by Skype. Sometimes he's a little detained in the morning because of Sydney traffic and his transport arrangements, but John will have the opportunity to catch up on the transcript anything he's missed, and I expect he'll be joining us relatively soon. So without further ado, would you like to state your name and, for the record, your organisation, and then to make an opening statement.

MS ROBERTS (S): My name is Bernadette Roberts. I'm manager of government relations at Scope.

MS HEGGIE (S): I'm Diana Heggie. I'm the chief executive officer at Scope.

MS SCOTT: Thank you for coming along.

MS HEGGIE (S): That's okay, and just in terms of an opening comment, I would like to just congratulate the commission in respect of this document. I really do believe it is a very comprehensive report, and will bring significant reform right across Australia, so I really want to just emphasise that first and foremost. I would also like to make the observation though, without the $6 billion of additional funding in this, that I actually don't think it's worth transforming with just the existing resources, because I've seen too many examples of states trying to bring in reform, with no additional resources expected, and it actually fails miserably, so I would like to really emphasise the need for the additional resources in this transformation process.

There are five areas that we would like to touch on today. We don't want to undermine in any way the principles of the model proposed, but we just feel that these could be enhanced, so that's basically the purpose of us briefing you today. The five areas that we're going to just talk to, and Bernadette will talk to in detail - I will just name them - are the social inclusion and community building, the first one. The second one is the workforce, and the minimum training qualifications. The third is the quality framework. The fourth is the supported decision-making, and the last one is the internal complaints around the governance. So they are the five areas that we would like to make comment on today, and I'll hand over to Bernadette and she will take you through the detail in respect of how we would like to see enhancements in those areas.

MS ROBERTS (S): I've written out a lot of what I'm going to talk to today, and I'll basically be reading that, but you're welcome to interrupt me as you'd like to.

MS SCOTT: Fine.

MS ROBERTS (S): The first comment we want to make is around social inclusion and community building. In the Productivity Commission issues paper, the government announced that this inquiry is an opportunity to rethink how we support people with disabilities so that they can engage with their community, get a job where possible and live a happy and meaningful life. Part of Scope's mission is to support people to achieve their potential in welcoming and inclusive communities and essentially that involves two main areas of support, and one of those is the direct services which is well covered in the report.

To make this happen, the other area of work that's required is community building. We think that the draft report addresses the first criterion well. However, if we are to support people to engage with their community and to live happy and meaningful lives, we believe that the second criterion must also be addressed. We acknowledge that tier 1 includes promoting opportunities for people with a disability and a lot of community building work could be covered there. What we're concerned about are the areas not as well discussed as the direct support services to people with a disability.

When it comes to community building and what that might entail, there are essentially three areas of work required. The first one for community building is actually individual person-centred work which we agree is well covered in the draft report. Probably the largest gap is identifying the opportunities that can be created within community. These kinds of activities include working with generic service providers to build their capability of supporting people with a disability. In tier 2 it talks about referring people with disabilities to generic service providers to receive the services. We think this is great, and people should be able to access generic services. However, we do acknowledge that there are times where people have difficulty accessing it because generic services actually don't have the skills required to meet their needs. We do think this can be met through training.

The second area when it comes to capacity building is around working with local communities, so a person with a disability shouldn't have to go to a disability service provider to go swimming or to go to the gym or to do anything that they should be able to do in local community. At the moment we do a lot of work with local communities to build their capacity to support people with a disability in their local environment, so with swimming pools, for example, we might support a local swimming pool to be physically accessible, to have the ramps, to have the hoists, to have all the necessary equipment that's required that a person with a disability might need, but we also provide the training. So developing skills in communication, for example, is an example of that type of training.

MS SCOTT: Good morning, John. I imagine that John and I would welcome any detail you could provide around how many hours involved in training and skills a facility like a public swimming pool would need, or a private swimming pool would need.

MS ROBERTS (S): Yes.

MS SCOTT: And what the costs of providing that service are. So anything you can add to assist us in terms of extent or cost would be most welcome, Bernadette.

MS ROBERTS (S): Okay.

MR WALSH: I guess, Diana, the other thing I'd like to add to that is the extent to which you think in a different market, in effectively a competitive type market, that organisations would develop these skills, and in any case if you wanted to attract business.

MS HEGGIE (S): The swimming pool is not going to do that because they'll charge the same charge for the person going into the swimming pool. Only last week we had a very good example, where a swimming pool, Coburg Leisure Centre here in Victoria, have put quite a bit of money into, and we've been involved in, assisting making that swimming pool accessible for as many people with disabilities as possible. So for example there's now an electronic hoist, there's a change table. They've even got a ramp that goes down to the pool level.

One of the things that happened is somebody with a very severe disability came into the pool. They had to be hoisted onto this special chair that then is wheeled down into the swimming pool, but the person couldn't sit in the special chair, and there was no wheelchair belt; you know, a whole lot of small things that were actually still barriers. And the staff are standing round the swimming pool looking at this, and thinking, "Well, how does this work?" So these things actually are about real local community capacity building, and they do require the skills and expertise of a specialist person to actually facilitate the gym or the swimming pool to understand that you're not going to make it accessible for all unless you can cover off on all these things.

So years ago we thought that just having the rail by the toilet meant that the pool was accessible. Now we know that accessibility for all is much more. It's more and more and more. It's about physical access. It's about attitude. It's about problem-solving. It's about being able to work that through, and I would argue that we need to build the capacity of our generic communities still quite considerably. They're a long way off, and we're talking about 360,000 people with significant disabilities here.

We need to build the capacity of those communities, and somebody has got to pay for that. The individual going into the gym with their package, the gym is going to be charging that individual the same as you or I. However, their costs are actually more in terms of accessibility. If they were costing that out for the whole community they'd have to increase the cost of the access to the gym. So that's an example.

MR WALSH: It would be really good to get a bit of a submission on how long you think it will take, if it's a forever thing or if there's a period of time - five years, 10 years - in which a revised scheme could focus on capacity building and what it will cost.

MS HEGGIE (S):   We'll take that on board in our written response back to you.

MS SCOTT: Bernadette, if there's an example where - and you've given me an example, Diana, of the Coburg Leisure Centre, where equipment is not necessarily the answer - you've been involved, and it's been a success, people have now felt confident and clients have felt confident, that would be good, too.

MS ROBERTS (S):   Yes, okay.

MS SCOTT: I don't know if you've noticed, but in the report we like to use examples because people find them very concrete and easy to understand.

MS ROBERTS (S):   I will make sure that the written report includes examples.

MS SCOTT: Thank you.

MS ROBERTS (S):   We do have a strong example in the southern region of Melbourne, where we work with neighbourhood houses, and I think there were approximately 81 neighbourhood houses that we worked with to make sure they were physically accessible and that staff were actually trained to include people in programs so that people just really could go to their neighbourhood house and not to Scope or not to - - -

MS SCOTT: Yes, great.

MS ROBERTS (S):   And that had great results.

MS SCOTT: Fantastic. Thank you. I'm sorry, we've interrupted your flow, but - - -

MS ROBERTS (S):   No. That's fine.

MS SCOTT: - - - it's very important that we get - - -

MS ROBERTS (S): You are more than welcome to interrupt as I go.

MS SCOTT: All right.

MS ROBERTS (S): The third level of community building is broad community attitude change, which I think you've addressed briefly in tier 1.

MS SCOTT: Yes.

MS ROBERTS (S): So our recommendation to you is that you consider including in the scheme community building grants. We think that could be administered in a range of different ways, whether it be state, regional or local bodies, and it can be included in tier 1 of the proposed scheme. We will put forward as much information as we can around what that costs, and the time frame as well.

MS SCOTT: Thank you.

MS ROBERTS (S): The second issue we want to talk about is workforce, with regard to minimum training qualifications. The statement that the commission does not recommend that certificate III or any other qualifications be a prerequisite for non-professional workers in the disability sector does concern us a little bit. Often, when an incident is investigated by the coroner, one of the first questions asked is, "What training did the staff undertake?" This implies that there is a level of training expected in some cases in order to deliver an adequate level of care. That is actually part of our duty of care, to identify that training. Equally, when an incident is reported by media, one of the first questions asked is, "What training did staff undertake?" Again this implies that there is a minimum level of training expected.

Under the proposed system, service providers will decide how to manage the risks and the level of training that their staff has. It will largely be service users that choose whether or not they want to pay for that level of qualification and those skills to determine whether or not it's important to them. In this market based system the level of quality, like I said, will be determined, predetermined by the person with disability. This assumes that the person with the disability and/or their family will carry the risks associated with untrained staff. Now, you've spoken about that in the report, and particularly I refer to a comment around the paternalistic nature of comments saying that people can't manage those - that some people might have with regard to people not being able to manage that risk.

What we think is that for people with profound significant disabilities and their families, the training benefits of a workforce are often hidden in the day-to-day struggle of actually managing life, where quality is often defined by service attributes such as a capacity for empathy, understanding, flexibility and personal experience, and that other practical skills learned through training are less understood and possibly not as highly valued.

The choice a person makes when paying high prices for services that possibly have trained workers or lower prices for unskilled workers requires significant information in order to make an informed choice. The person must understand that they will carry the burden of risk and the consequences of that decision, which you are articulating in the report in various ways. Our recommendation to you is that you apply a modified test of reasonableness and necessity that you use to decide similar criteria for whether the services are appropriate or not and that this criteria can be used in the determination of minimum training qualifications.

MS SCOTT: Bernadette, this is a good point to, I think, have a chat. I'm very taken, and I'm sure John is too, with some of the features of the lifetime care arrangements in the New South Wales scheme. In relation to attendant care, the assessment process identifies the level of qualifications the attendant carer needs. That's for catastrophic injuries.

MS ROBERTS (S): Yes.

MS SCOTT: Now, because we're talking about people who will need very little support to lots of support - very different skill sets, decision-making assistance versus potentially nursing care at the high end - we thought the assessment process would do that, and I think you're just saying that back to us. What we may not have done is articulate that well enough in our documents. Do you think we're on the same wavelength? What I'm thinking is, if an assessment process was centred on a person who needed decision-making support, then that would be particularly noted and that would be the skill set of the person that would be providing the care.

MS ROBERTS (S): Yes.

MS SCOTT: If the person needed high-care nursing support, then of course you'd need high-care nursing support. Some of our people who attended yesterday - Jess and George - once again reiterated their concern that they didn't want qualifications to stand in the way of the personal attendants that they wanted to choose. So it's horses for courses. Are we on the same wavelength?

MS ROBERTS (S): Yes, that is consistent with what we're saying.

MS HEGGIE (S): It would be on the same wavelength. I mean, for people like George, who are able to make informed decisions and can actually say, "Oh, that's it," and they've noted it, then it's all there, but we are talking about people without that capacity - very significant disabilities - and the notion that if something happened - an incident in the community; they choked, or pneumonia - aspiration pneumonia, that's one of the major causes of death in the field that we're supporting.

MS SCOTT: Of course.

MS HEGGIE (S): The expectation of the community would be that the person supporting that person in the community is trained, because we've been in coronial inquests, we know it's a non-adversarial process, but the constant expectation of the community is that the people supporting somebody with that level of disability have a minimum training of some kind. So it's about reasonableness and what the community would expect in terms of the support being provided to that person. If they cannot make an informed decision, and really independently make an informed decision, then there has to be some mechanism there that would ensure that there will be some minimum.

MS SCOTT: John, do you want to come in here?

MR WALSH: It's something we need to explore further. I mean, I'm reminded, I guess, of people's choice in determining what medical assistance they want, but there is a formal process for going through that, and maybe we can go down that line. If people are prepared to make, effectively, a directive that they will take responsibility for the quality of the care they receive, and they have the wherewithal to do that, maybe that's a way around this.

MS HEGGIE (S): Yes, that's the key. If they've got the wherewithal around it, there's absolutely no question about it. Our actual concern is that most of the people that we are supporting in terms of making an informed decision around major issues in respect of their health care and wellbeing may not be able to make that decision themselves.

MR WALSH: As you guys would be aware, there's an entrenched feeling in the area of disability that people are given what's put to them. They don't have a lot of choice in what they receive.

MS HEGGIE (S): Yes.

MR WALSH: We need to change that. We need to flip it on its head.

MS HEGGIE (S): We do. We've no problems with that at all. I just am concerned for the group of people I've spoken about, and I think we have to have a mechanism there. They are too vulnerable. If things do happen, it's about community expectation and what they would say is reasonable in this case.

MS SCOTT: Sorry to interrupt, Diana, but can I just explore that a bit more. It seemed to me that both you and Bernadette are highlighting this community expectation factor. In some ways it's like a press expectation factor.

MS HEGGIE (S): Yes.

MS SCOTT: It could be a press expectation factor; it could be a coroner expectation factor.

MS HEGGIE (S): Yes.

MS SCOTT: We estimate that 80 per cent of the cost of the scheme is likely to be in attendant care but we know most of that attendant care at this stage is unlikely to require high levels of qualifications. So in some ways we probably have a role as a commission to educate people or to explain better that fact. If people are going to imagine that everyone has a certain or a high level of qualifications, (1) the affordability of the scheme would be jeopardised; and (2) the workforce is unlikely to be available.

MS HEGGIE (S): Yes.

MS SCOTT: So there's a clear trade-off here, and I wonder whether expectation management might need to be part of the task as well.

MS HEGGIE (S): I think it is, because people look at somebody with a very significant physical and multiple disability - who may be well able to make an informed decision and make choices - but they just assume, as a community, that these people should be being supported by - - -

MS SCOTT: That's right, yes: "Where's the doctor?" "Where's the nurse?"

MS HEGGIE (S): Yes. So perhaps it is in education and awareness raising, but you're going to have to invest in that, because the downside is that if you do have instances you do then have - - -

MS SCOTT: Yes, and you will have instances.

MS HEGGIE (S): And you will have, and then you have the reports and then you have whatever follows that. We're just saying that it is actually something that has to be looked at - and maybe for only 36,000 of the 360,000 people, but it's a significant group of that that you need to think maybe slightly differently about.

MS SCOTT: All right. That's very constructive. Thank you very much.

MS HEGGIE (S): Yes.

MS SCOTT: I suppose I'd better let Bernadette move on. John, are you comfortable with that?

MR WALSH: Yes.

MS ROBERTS (S): I was just going to add to the conversation that the other concern around this stuff is that the person who's providing that support actually understands some of their rights and responsibilities as well. So, for example, with manual handling, we resolve many issues with the way that families and people with disabilities actually want to get around, whether it be from their chair to their shower chair or whatever, however it might be, and often families and people with a disability want us to do things that we don't consider are safe in terms of our occ health and safety manual handling types of requirements. So there are some activities where there does need to be some type of training.

MS HEGGIE (S): There is an example and it's a report and it's on public record, and it is a coronial inquest. I'm not going to name the organisation or name anything, but it's a very good example. A person living in their own home, a man in his 40s, I think it was MS, right? The carers came in. They'd been trained how they were to use the hoist and the hoist gear. He said he didn't want it done that way. He had his way - and he's the person at the centre here, so they were to do it his way. They did it his way. He fell through the hoist, died; hit his head on the floor. That went to inquest and the carers were found to be negligent, in that they should have done what their training had told them to do. It is a written example and we can reference that in a report to you, but it's just one example whereby we have to be mindful of some of the stuff around training and person-centredness.

MS SCOTT: I think that would be very good, if you can reference that case.

MS HEGGIE (S): Yes, okay.

MS SCOTT: We will follow that one up.

MS HEGGIE (S): Yes.

MS SCOTT: One of the things we were trying to get across - maybe it was, again, subtle - in the governance chapter was this idea that you can have a government organisation, or even an organisation that's not government based but community funded or partly community funded, where you have this sort of kneejerk reaction; like, try and eliminate all risks, and we can't eliminate all risks ever. We can attempt to manage them or minimise them. So we might be able to use this example you've given us as food for thought for our own thinking processes.

MS HEGGIE (S): Yes.

MS SCOTT: All right, thanks, Diana. Now, Bernadette, you've probably got some - - -

MS ROBERTS (S): Okay, I'll keep moving on.

MS SCOTT: Yes.

MS ROBERTS (S): The quality framework: Scope supports the development and implementation of a quality framework for disability providers. We believe that all providers should meet the quality framework. The application of the disability standards is relevant to all providers of support, including those providers employed by a family or person with a disability, whether they be family members or neighbours. The issue that you - - -

MS SCOTT: Sorry - because of the points you made earlier about how we're anticipating that with the right arrangement and the right encouragement and progression of the market that quite a few services will actually be provided by generic providers, we have to be careful about using the word "all" all the time, because in our thinking it's going to be the case that some services will come from the mainstream; just as they do now, but hopefully more. Therefore, we did deliberately use the phrase - I think I'm going to try and do it from memory - something like "all funded specialist service providers".

MS ROBERTS (S): Yes.

MS SCOTT: So you would like that to read "all funded specialist service providers, disability support organisations and"?

MS ROBERTS (S): We would like to see - I mean, just to simplify it - that all service providers are funded by NDIS. I know you've got the issues there with the generic service providers. What we're saying is that any activities that are funded by the NDIS should meet disability standards in principle. The quality framework and how to do that: there's a difficulty with costs and we recognise that, but we do think that any services that people with a disability are funded to receive should meet disability standards.

MS SCOTT: Noted.

MS HEGGIE (S): In order to ensure some sort of quality for people. So it's a hard one I know, and it is a costly one, but we think that that's reasonable.

MS SCOTT: Okay.

MS HEGGIE (S): Okay? Noted.

MS ROBERTS (S): The next point is around supported decision-making and market forces. We welcome the focus on increasing the power of people with a disability and their families to choose their supports. The market model proposed is founded on the principle of people with a disability being well informed and supported to make decisions. Scope believe that this will require considerable investment - and you have referred to that throughout the document. The part that's not referred to is what we call "supported decision-making". So you refer often that people with a disability will be provided with information, whether it be through the disability support organisations or the case managers.

Families play an important role in the lives of people with a disability. However, the power a family has in making decisions as a proxy or on behalf of the person with a disability doesn't always include the wishes of the person with the disability. There are often different perspectives on what is deemed to be in the best interests of someone and, in particular, in the provision of care provided to a person with a disability. We are acutely aware of the challenges faced by what we call "circles of support" in coming to a consensus around what is in the best interests of the person they care for and about. Scope would like to see supported decision-making training that guides people with a disability and their carers in how to develop plans and determine satisfaction with services and that respects the rights and responsibilities of both the carer and the person with the disability.

MS SCOTT: Yes. I understand that.

MS HEGGIE (S): So we just want to see that - and it may be that the training for that has to be in block funding or something and given out separately, but we need to ensure that it's there.

MS SCOTT: I was envisaging that this would be an element in some ways of the phased rollout of the scheme, that really someone wouldn't turn up to the NDIA without having already had information sessions - you know, "Here's a video that explains how things will work," a visit from the local case manager and so on. Could you tell me how many sessions or what would be the time frame - I know everyone is different - for the sort of families and clients that you look after and deal with? What sort of training or assistance would need to be provided before someone would turn up to have their assessment and discussion about their individualised plan?

MS ROBERTS (S): It does vary. I'd prefer to look into that and give it to you in - - -

MS HEGGIE (S): In writing.

MS ROBERTS (S): Yes, in writing.

MS SCOTT: Okay, that's fair enough. All right, I'm conscious of time.

MS ROBERTS (S): Just the last ones, very quickly. Basically, we understand the issues that you have with internal and external complaints mechanisms and the cost and the sustainability of the scheme. Our preference is for an internal complaints mechanism. However, we would not want the sustainability of the scheme to be compromised like that, but overarchingly the scheme itself is going to transform - - -

MS HEGGIE (S): Our preference is for an external not an internal.

MS ROBERTS (S): External. I said "external". What am I saying? Sorry.

MS SCOTT: You said "internal".

MS ROBERTS (S): Yes, external. And it's got to do with all the things that you talk about and why people would argue for it. Looking at the costs of it: if it undermines the scheme, then it would have to be internal. One of the things that we spoke about - you say that could be at arm's length. Without going through a whole different process and all the rest of it, can it report directly to the NDIS board and not be wrapped up within the National Disability Insurance Agency?

MS SCOTT: Yes.

MS ROBERTS (S): In the document I read it as that you had it reporting into, for example, the CEO at some point in the NDIA. You don't say that, but it's wrapped up within the agency.

MS SCOTT: I see. All right. I think we described it as a separate office.

MS ROBERTS (S): Yes.

MS SCOTT: And a statutory appointment. We could make the lines of reporting clearer, but certainly under some Commonwealth legislation - under, for example, freedom of information - the CEO of an organisation cannot seek to influence and cannot be seen to influence, cannot influence the decision-maker on FOI requests.

MS ROBERTS (S): Yes.

MS SCOTT: So you can actually have an arrangement where effectively the CEO has to stand aside, so we could look at a variety of other arrangements. I think it's important that the board knows what's happening on the complaints structure. An issue could be that maybe - now, this is just talking in just a discussion way - if the line of reporting is to the CEO but not through anyone else, there may actually be strength in that in the sense that the CEO hears, "Right, okay, we seem to have a problem with the Sale or the Gippsland region. We have a problem there." I mean, the board is meeting, say, once a month. Why would you want to leave something for three weeks before someone knew about it?

MS ROBERTS (S): Yes.

MS SCOTT: So just the idea that they shouldn't have to go through lots and lots of managers, I think. We're talking about a senior appointment, a senior person who can stand alone from the organisation, but just for your own thinking, you might wonder whether a non-reporting to the CEO is in fact a good way of doing it or not.

MS ROBERTS (S): A good way of doing it, yes.

MS SCOTT: I can see strengths and weaknesses in both arrangements. I haven't got a firm view. John, are there questions you'd like to ask Diana and Bernadette?

MR WALSH: Your evidence looks like it's balanced towards maintaining the service provider as having a position of considerable power in the provision of services. I'd like some feeling in your submission around how you see the development of individual decision-making.

MS HEGGIE (S): I think the notion about the service provider still maintaining power - I don't actually know that I'd agree with that, but I'm happy for you to have that view. I do think that for the people we're supporting in this scheme - and we are talking about some people with very significant disabilities - the community is still a long way off being able to just be the provider out there. So I would like to see some investment in that, whether it be hub-and-spoke type models, so you've got some specialist hub that can go and support and put a lot of effort and work into hub-and-spoke type arrangements, to make the community - it's a bit like quotas on boards. You know, it ain't going to change substantially unless there's an investment of resources in the community side of things. So I would say that, until that investment is made, you are going to need specialist providers. That is my view, and I don't see the investments being made.

I mean, I can tell you in terms of the tram. I'll give you an example: Bundoora university here. I can't remember which tram it is. Say it's tram 78. They've spent millions and millions and millions of dollars on making lovely accessible stops where you can come up in your wheelchair, up onto that ramp - millions of dollars - and do you know, the tram will rock up and there are steps, and you ask them, "How long is it going to be before the tram that comes up to the stop can actually take the wheelchair?" and they'll tell you 10 years, John. Now, I'm sorry, who is actually speaking and advocating and working with the community to say this is just not okay? I don't see the evidence so, yes, I am not afraid to say there is a strong need for specialist providers who have knowledge, who are prepared to advocate strongly on these topics. Currently today we are not there, and if you don't invest, and there isn't an investment, we're going to go even backwards further.

MR WALSH: I'd welcome some information on that, but also I was wanting to get at the individual relationship between the person with the disability and their support worker, and the ability of the person with the disability to instruct those in the way they want that service to be provided.

MS ROBERTS (S): Yes. I think one of the things is we have spoken only of a couple of key issues that we have, and what you've heard is just that stuff. We think the market that you're envisaging will give power to people with disabilities and at the heart of that is their - "ability" is the wrong word but they will be empowered to make decisions about things that affect their lives. We completely support this. What we do want to emphasise though is that the whole model is founded on those decisions being in an informed way and also in a supported way, where the rights of both the person with the disability and their proxies are balanced. This should develop over time in a market environment.

MS HEGGIE (S): I think people do need to have a circle of support around them, because it's not just them or their parent. It may be other people in their lives. There are models and they are referenced, so I think the support needs to go into those.

MS SCOTT: Diana, we did try to make reference in the assessment process to - you know, it wouldn't involve just the individual in some cases. It would be appropriate for other people to be involved and so on. We're not too proud to suggest that if people see actual drafting changes - you know, the inclusion of a few words here, or clear paragraph there, or you might need to reference this study or that inquest - we're more than happy for people to give us quite clear suggestions about what they'd like to see in the final report. We don't have long. We will investigate what we can, but the team is not 4000 people. It's a group of about eight to 10 people, so if you can assist us that would be good. Just one last question, that case of the Bundoora tram line - I hope I've got the right - - -

MS HEGGIE (S): Yes, 78, I think it is, the number 78.

MS SCOTT: Is that in the public domain?

MS HEGGIE (S): Yes.

MS SCOTT: It is. And was there any government or community reaction to that?

MS HEGGIE (S): Yes. We even took it to the media and the public and we got response, so we can give you that. We can give you that.

MS SCOTT: Okay, yes.

MS HEGGIE (S): My opening comment was - I'm not sure whether John was actually here at the beginning - - -

MS SCOTT: No.

MS HEGGIE (S): - - - that I was incredibly supportive of what is in this reform. I believe that it will change the dynamics in the power base, so I in no way want you to feel as though I'm actually agin it, because I'm not.

MS SCOTT: No.

MS HEGGIE (S): I seriously think it is a magnificent piece of work, and I support it a hundred per cent. Our issues today are about enhancement and are about additional resources that I think need to be invested to make a better world for people with disabilities.

MS SCOTT: All right, thank you.

MS SCOTT: I call to the table the Law Institute of Victoria.

MS DUBROW (LIV): Hello, I'm Dimitra Dubrow. Hello, John, I'm Dimitra.

MS SCOTT: Dimitra, don't be worried by the size of the crowd at the moment. All right.

MS DUBROW (LIV): That's quite all right.

MS SCOTT: Welcome to the public hearings. Would you please identify yourself for the transcript, and the organisation which you're representing, and we've assigned 30 minutes to your presentation, but as you can tell from the first presentation, anticipate some questions along the way.

MS DUBROW (LIV): Yes, indeed. I'm Dimitra Dubrow and I'm here to represent the Law Institute of Victoria and provide some comments about the report. So in that capacity I'm going to be very much, though, seeking to represent the views of the Law Institute. May I start?

MS SCOTT: Yes, please do.

MS DUBROW (LIV): First of all, the Law Institute welcomes the Australian government's initiative to address this urgent need to provide better and improved care and support for people with disabilities, and to provide it to more of our citizens. There's little doubt that there needs to be an improvement on the current levels of care, and there's certainly a sense that there's unrealised potential, and an over-reliance on unpaid family members. So we do support the introduction of a scheme that ensures an increase in the funding for disability care and support services, and improvement and levelling up of the standard of care, and more choice and autonomy. So today I'm just going to comment on some areas of the report obviously.

First of all the Law Institute supports the introduction of a single scheme. We can see why from a funding point of view - and jurisdictional considerations may have led to a proposal for two schemes, but we advocate the establishment of a single scheme for people with permanent significant including catastrophic physical and/or intellectual disabilities, and those in need of earlier intervention. We see that two schemes will involve extra administrative costs, and may be unnecessarily burdensome.

There's also the issue of definitional disputes, as people struggle to contend with, "Well, do I come under the NIIS or do I come under the NDIS?" We also see that there's scope for inequities to flow. So we see that the NIIS in terms of medical cases is to cover people who have received medical care that's not been provided in a timely or appropriate manner but not cover people with genetic or underlying health conditions.

This would seem like an anomaly to us because it would result in people with the same level of disability being treated differently under the scheme. So people with a genetic or underlying health condition would need to revert to the NDIS and not be able to receive the same level of care provided or envisaged by the NIIS. Instead, they'd be contending with what might appear to be a lesser set of benefits under the NDIS. This, to us, seems to be quite arbitrary, and also it seems to introduce an element of fault and causation in a scheme that purports to have a no-fault basis. In some ways this highlights: why is there a need for two schemes? Shouldn't the question be need and not cause?

We would submit that fault and causation should remain within the domain of the common law, which has developed concepts of negligence and causation and has sought to strike a balance between certainty and flexibility to reflect changing values and the changing needs of our society. We query why parallel notions of fault should be introduced into the scheme.

The other area of inequity is that, as we understand it, the NIIS would cover only new cases of catastrophic injury and the old ones would come under existing care of the NDIS. Again, we just wonder why a person should receive a different level of care just because of such an arbitrary thing as the timing of their injury.

Moving on to the difficult issue of what to do about some states that do not have an equivalent type of no-fault scheme. I guess the TAC is mentioned a lot in the report, and we do agree that there appears to be no rational basis for the difference amongst the states, and that there is an urgent need for those gaps to be filled for states - I understand it's Queensland, Western Australia, South Australia and the ACT - to introduce no-fault coverage for those catastrophically injured in motor vehicle and industrial accidents.

The way we read the report, it's difficult to see how the federal government could encourage or get those states on board to introduce such schemes when there appear to be no federal powers to enable legislation to be put into place. One way may be that the Australian government considers taking on the responsibility for funding the entire cost of a single scheme but on the basis that the Australian states and territories do introduce no-fault catastrophic injury schemes for motor vehicle and industrial injuries akin to that provided by the TAC. In other words, those states introduce those schemes, and the Australian government fills the gap otherwise, by providing coverage with significant and catastrophic disability being covered under the scheme regardless of the cause.

In any event, if two schemes are considered necessary, the two issues that we want to really convey are that we don't think the criteria should be such as to introduce elements of fault and to only cover new cases of injury, again because of those inequity issues. Was there anything arising from that, or shall I move on to my next - - -

MS SCOTT: I wouldn't mind exploring with Dimitra just the issue of practicality. I think, on the basis of equity, you are on strong grounds for thinking why should a date have anything to do with outcomes? Of course, we don't start with a blank piece of paper. We have schemes that are in existence now. We don't have an NDIA in existence, and there's the practical question of what can be accomplished. So I'll have to say that had a bearing.

Does that affect your own thinking? I mean, you seem to be acknowledging that it would be best to have one scheme, but if there are two schemes - so just as I think we've acknowledged that there might be, in an ideal world, merit in having one scheme, but we don't have an ideal world. We have a number of constraints and one of them is the capacity of a scheme to accommodate everybody and to accommodate everybody well for it to be financed, and when we have some well-functioning schemes in existence. I would be interested in your comments on the practicality of a scheme, including accident cases that are 30 and 40 years old, when there are actually very small schemes in existence now.

MS DUBROW (LIV): Yes. Obviously there are a number of questions that arise from the report and it's difficult to find solutions for those questions. We recognise the huge task at hand, and there are no easy answers. Unfortunately we are limited in what we can provide in terms of solutions. What I will discuss later is the funding. Obviously the funding requirements are huge, and I will discuss this - and perhaps now might be a good time - - -

MR WALSH: Just before you go on to funding, Dimitra, I wanted to come back to the issue of a single scheme for a minute.

MS DUBROW (LIV): Yes.

MR WALSH: You said that ideally there should be just one scheme for all types of severe disability, regardless of cause. Is that correct?

MS DUBROW (LIV): Yes.

MR WALSH: You would abolish the common law head of damage of future care and support?

MS DUBROW (LIV): That was actually the next topic that I was going to address. No, the Law Institute does not support abolishing the ability to recover compensation for long-term care. Is that something I should discuss now?

MS SCOTT: I think it would be worthwhile if you went to that now.

MS DUBROW (LIV):   Okay.

MR WALSH: In the context that, as you've already said, there should be just one scheme providing support for people with major disabilities.

MS DUBROW (LIV):   Yes. Obviously there are a number of reasons why we support retention of the common law, but we also think it may actually assist in providing some revenue for the scheme. So the Law Institute does support a no-fault scheme that's complementary but maintains common law rights.

MS SCOTT: In fact, it could be actually re-establishing common law rights in some cases, in some jurisdictions.

MS DUBROW (LIV):   That's an interesting point that I don't think I could comment on in the sense that where current state schemes have limited or impose thresholds - - -

MS SCOTT: Either impose thresholds, or simply extinguish the common law right.

MS DUBROW (LIV):   I know that there are certainly limits - and I'm speaking as a Victorian, so I know that in TAC and WorkCover you need to reach a certain threshold of injury before you can pursue common law rights.

MS SCOTT: All right. But in those cases, you'd be eliminating the thresholds and effectively reinstituting?

MS DUBROW (LIV):   I'm not in a position to comment on that, and that's certainly not something in our submission that needs to be revisited.

MS SCOTT: But wouldn't that be a consequence of what you're suggesting, or not?

MS DUBROW (LIV):   Not necessarily, but if it would be all right, John and Patricia, I would like to take that on notice and take that question back to the Law Institute because that's not a matter that I'm able to address today.

MR WALSH: The other similar one, Dimitra, is (audio cut-out) Tasmania and New South Wales there is no common law right to receive damages for future care and support, so you'd be unwinding that, I presume?

MS DUBROW (LIV):   I wasn't here to address unwinding any particular rollbacks that have already been introduced, but I would like to take that back to the Law Institute, to seek a considered response to that, if that's okay. What I'm seeking to discuss today is maintaining the ability to sue for long-term care and not have that taken away in the catastrophic injury category.

We have noted that there are a number of negative comments in the report about the role of the common law, so if I could just address some of those. We do think that the common law still has an important role to play in risk management and deterrence and in achieving a sense of justice for an injured person. It would be an affront to a person who has suffered an avoidable injury as a result of negligent wrongdoing not to have a remedy to sue for all damages, including long-term care. Yes, in many cases damages are paid for by insurers, but there is an impact on premiums, there is a need to pay a deductible, there's reputational damage, and the focus of insurers on implementing risk management strategies.

In our view, that does result in improved safety standards and the avoidance of risky behaviour. I think that the area of industrial accidents is a case in point. We have seen, as a result of the development of the common law, certainly a contribution to higher standards now required of employers, and much the same could be said about asbestos litigation in terms of achieving accountability and medical litigation. We don't think that the equivalent level of deterrence could be achieved with a no-fault scheme. Even taking into account a form of risk rating which is discussed in the report, we do think that a no-fault scheme can't achieve the same level of deterrence because the incentive to investigate and inquire into risky behaviour systems won't exist.

MR WALSH: Can I just comment on that, Patricia?

MS SCOTT: Please do.

MR WALSH: I'm not sure if you're aware of it, but the issue of workplace compensation is not really in the report, so the industrial issues I think are outside the scope of what we're talking about. But could the Law Institute please provide examples where deductibles and impacts on premium are used in motor vehicle insurance?

MS DUBROW (LIV): Provide examples? So first of all, in relation to workplace compensation, I take your point, John. That was more in terms of an example. If we look back over the last 100 years, the common law has contributed to where we are today in terms of the expectations of employers. That was the point I was seeking to make. You would like the Law Institute to provide some information - data I think is what you're asking for - is that right? - on the impact.

MR WALSH: Information on where deductibles are used in Australia in compulsory third party insurance as a deterrent effect.

MS DUBROW (LIV): Can I take that back to the Law Institute and - - -

MS SCOTT: Yes, we're happy to take information by email. We'll be having discussions, obviously, following the hearings - you know, what information we're anticipating back and so on - so we'd welcome an early indication of whether you will be able to provide that material. That would be great.

MS DUBROW (LIV): The Law Institute is intending to provide information to the Law Council of Australia, so it may be through the Law Council of Australia.

MS SCOTT: Okay. Thank you. Please proceed.

MS DUBROW (LIV): The report also talks about the length that cases take to resolve and come to finalisation, and there are some pretty high years being quoted. I'm very glad to say that cases taking more than 10 years are the exception rather than the norm. They are the extreme cases. Anecdotal reports would suggest that most common law claims are resolved within two to three years and some of them are four to six years, depending on the age of the person and the complexity of the litigation. Some medical negligence claims do take - we've noted the reference from the Victorian Senior Master's Office to nine years but, as we understand it, that's nine years from the date of the injury to the time of the resolution.

We now have reduced statutes in most states, as I understand it. Certainly in Victoria a person has three years to commence a claim and for a child it's six years, so I do think that those excessive delays are a thing of the past. We don't necessarily think that removing long-term care will decrease or improve on the delays. Liability can often remain an issue right to the very end and it's not going to be the case in all of the cases that there will be a speeding-up of a process and problems with delay will fall away just because long-term care has been removed. We're also concerned or have a question about the assumptions in the report about the amount required for long-term care in chapter 15 and that seems to be an underestimation. I think the amount mentioned in table 15.4 is $2 million, whereas our anecdotal reports would suggest that lifetime care costs can be upwards of $3 million, depending on the severity of the injury and the age of the person.

I think I mentioned earlier that we think that maintaining long-term care in a compensation claim would have the potential to actually assist with the costs of the scheme. A person who succeeds in recovering compensation could be under a legislative requirement to repay any funding that they've received from the scheme and even have a preclusion period imposed on them, calculated on the amount of damages they've received for long-term care. So that would ensure that there's no double dipping, some funds coming back into the scheme and less people in the scheme because there would be a certain proportion of people who will have their damages to cover their long-term care needs. That's a suggestion that would be akin to what now happens with Centrelink, so if a person brings a claim for loss of earnings there's a preclusion period and there's a requirement to repay some benefits that have been paid in the past.

MS SCOTT: Do you think those preclusion periods work in the case of payouts?

MS DUBROW (LIV):   In the Centrelink situation?

MS SCOTT: Yes.

MS DUBROW (LIV):   Yes, they do. Centrelink have a particular formula which in some cases - they utilise a formula where half of the compensation is considered to be for loss of earnings regardless of the component. So in that sense in some cases there might be a period that's - well, I can't comment, but in some cases that might result in some difficulty. But if it was applied to the amount of long-term care actually paid or agreed to by the parties as the amount representing long-term care, then that should bring about some ability of the person to utilise their own funds. The schemes won't be having to cover that care cost and the person can then come back into the scheme if that preclusion period has been reached.

MR WALSH: I'm struggling, Dimitra, to understand the logic here. So you're suggesting that someone still goes through common law for future care and support and reach a lump sum.

MS DUBROW (LIV):   Yes.

MR WALSH: The option you've suggested is that they then pay that back to the NDIS?

MS DUBROW (LIV):   No. Sorry, I haven't expressed myself very well. No, what I meant was the person who is successful in achieving compensation for the injury, which would include long-term care, would repay to the scheme any funding or benefits they have received under the no-fault scheme that's being envisaged to be introduced. In addition, to deal with future care, they would be precluded from being under the scheme for a certain period of time, which would be calculated by reference to the amount of damages paid for the long-term care. So repay what you received in the past.

In fact, that currently happens under some guidelines with some programs, so in Victoria we have something called the Aids and Equipment Program. There are guidelines that say we are to notify them of a compensation claim. We don't know that all people and recipients of compensation are aware of that. So we notify the scheme that a claim is being pursued and at the successful conclusion of the claim we repay whatever that program has funded a person. It might be $8000, it might be $10,000. Those funds go back into the scheme.

MS SCOTT: So, Dimitra, have I got it right? Let's say a person has an accident and the scheme would be there to assist them and provide them with care and support. They would avail themselves of their common law rights, if they wish. Let's say after X period of time they would receive then some compensation; part of that compensation would be used to refund the scheme for some of the costs that they have experienced as a result of the individual. The individual would leave the scheme but at some point in the future the scheme would stand ready in the event that the person's funds effectively ran out, and they would stand ready to look after that person.

MS DUBROW (LIV): That is what I'm putting forward, except for the last point, which would be that instead of when the funds run out - which might not encourage a person to properly manage their funds and make them last - it would be a date set in the future. You receive $2 million for long-term care costs. That should be sufficient to cover you for a certain period of time. You cannot come back into the scheme for 15 years, maybe even 30 years.

MS SCOTT: So this is an acceptance then that the compensations received by people for long-term care and support through the common law system are not sufficient for actually their long-term care. That's what you're saying?

MS DUBROW (LIV): It's actually not what I'm saying. I was going to go on to say that compensation for long-term care is likely to be a greater amount than any amount that would be provided under the scheme. So yes, in some cases the compensation that a person would receive for long-term care would probably ensure that they never need to come back to the scheme.

MR WALSH: Dimitra, shouldn't that always be the case, because they are compensated for lifetime care?

MS DUBROW (LIV): Yes, and I do think that in many cases that will be the case, but as a safety net there should be a formula. What that formula should be, the detail around that, can be looked at later. That would ensure that a person wouldn't dissipate the funds and simply come back and say, "I don't have any damages. I need to come back into the scheme." So there would be a formula to calculate the period of time that you can't come back into the scheme and that's likely to be, in many cases, lifelong.

MR WALSH: Who would pay for the future costs when the person does come back into the scheme?

MS DUBROW (LIV): By application of a particular formula.

MR WALSH: But if common law is meant to pay for the lifetime care of the person, who would pay for the residual cost to the NDIS?

MS DUBROW (LIV): I'm not sure if I've understood the question, but I'm envisaging that in many cases there will be no coming back into the scheme.

MS SCOTT: Where there is some coming back into the scheme, who bears the cost of that?

MS DUBROW (LIV): I think the proposal would be that they would come back into the scheme.

MS SCOTT: So the general revenue would effectively cover the cost of those individuals?

MS DUBROW (LIV): Yes, but we are envisaging that that's going to be a rare occurrence. In terms of equity, I think there needs to be some kind of formula.

MS SCOTT: My own experience of running human services at the Commonwealth level was that on the books it can look like you can have very good preclusion arrangements to all sorts of formulas, but actually if the people in front of you don't have any means of survival, the funds are dissipated. It's very difficult for governments. Even if officials can say, "Well, I can't possibly allow you to come back into the scheme," it's often very difficult for politicians to argue that things should be relaxed to allow people in need - - -

MS DUBROW (LIV): Yes.

MS SCOTT: Do you have a suggestion for that? I guess what I'm drawing attention to is the difference between something that says, "The legislative formula says you will not be able to receive assistance for 18 years," and then the fact that after nine years people can find that the global financial crisis, or gambling, or addiction, or very poor management or, you know, a celebrated case of accountants or even, dare I say it, lawyers running off with the money, or using the money unwisely - I just want to get your view about the effectiveness of preclusion periods in cases like that.

MS DUBROW (LIV): I think when one hears about those terrible cases where funds have been dissipated, or people in good faith have invested them with people that they shouldn't have, or unwittingly, certainly they are obviously tragic cases. Again, I think that they are the exception rather than the rule. I think the preclusion period could work quite well. Whether there's a possibility for a hardship application, that's something that further thought could be put to. I hear what you're saying about any formula, even if it's the most sophisticated one, will raise some problems. That was one way to ensure that there's not double dipping.

MS SCOTT: Yes.

MS DUBROW (LIV):   So if you do recover, you don't then go into the scheme, obviously, and that allows funds from the scheme to be utilised for other people in need.

MS SCOTT: Thank you. John, I'm conscious that we've only got, now, probably another five or 10 minutes with Dimitra. Do you have much more to go?

MS DUBROW (LIV):   I was going to talk a little bit more about the common law, but really we've touched on it. The fact that a common law damages payout is likely to be - even with some compromises in the claim for risks which have been discussed in the report, it's probably going to be a higher amount of funding than is going to be received under the scheme, and the person would have complete autonomy.

As I said before, the risk of dissipation is fairly small and there's really no comparison in terms of freedom of choice. They would not be tied to a prescriptive scheme. In terms of the TAC scheme in Victoria, it is held up as a case of best practice for a no-fault scheme, but even with that scheme, the care and therapy is necessarily limited, and it's subject to review and involves a long-term engagement; a lifelong engagement with the scheme and the eligibility criteria. We would see no reason why the common law can't be maintained, and we are talking about a small group of catastrophically injured people who are entitled to compensation and we say that they should be able to exercise that right.

The next thing I wanted to talk about was funding and this has already been touched on, of course. We would want to be sure that the scheme is adequately funded, because the flow-on effect of it not being adequately funded is obviously going to mean a compromise on the standard of the benefits provided. We want it to be properly costed. We don't want to obviously go down the New Zealand path so, in the funding, we'd like there to be the kinds of risks that have befallen that scheme to be factored in.

We've noted the proposed source of funding for the NDIS and we see there that there's a mention of a further amount of funding of $6.2 billion. We wonder whether that has taken into account the broadening of the definition of disability and we welcome the broadening of the definition to include cases of degenerative disease, but in calculating the extra funding that's required we hope that that has been taken into account. Of course - and again this has been touched on - there's increased demand for disability support staff, with the result of wage increases, and the fact that a lot of the care is currently by unpaid carers; family members. Our concern is that if there's an underestimation, well, you're not going to provide the level of care; we're not going to improve on the existing care. We wouldn't want the scheme to be in jeopardy and crumble away because there's inadequate funding.

The two last things I wanted to talk about again have been touched upon: the assessment tools; the requirement to provide reasonable and necessary supports. Of course it appears appropriate, but there will be definitional disputes around that. Similarly, the proposal that the scheme not pay for services for which clinical evidence of benefits is insufficient or inconclusive is also likely to give rise to definitional disputes and we wouldn't want to see people caught up in a mire of bureaucracy and definitional disputes. We would say that there would be some therapies and interventions that would enhance a person's life, even though they might not actually be defined as reasonable and necessary under the definition.

MS SCOTT: Do you have an example of that, Dimitra?

MS DUBROW (LIV): Again I will need to come back to you on that.

MS SCOTT: It would be good to have that.

MS DUBROW (LIV): Yes. Perhaps we'll go through at the end the things that we will come back to you about. The review process envisaged in chapter 7, we do advocate an external review process. A merits review that is purely internal we say would not be sufficient to ensure independence and we would advocate the proposal that there be a specialist with the AAT set up to hear appeals on the merit and that people should be able to be assisted, including by retaining a lawyer, in any review process. That covers the things that I wanted to talk about.

MS SCOTT: Thank you.

MS DUBROW (LIV): I just want to make sure that when I go back I cover everything I have here. The first one is in relation to whether we'd be talking about changing any of the existing schemes to bring back some rights that have been rolled back. The second is the impact of premiums and deductibles on compulsory third party insurance. I think the last one is examples of how the definition or the requirement that the scheme not pay for services for which clinical evidence of benefits are insufficient or inconclusive - to give you some examples of that. Is that correct?

MS SCOTT: Yes, that is correct.

MS DUBROW (LIV): Are there any other - - -

MS SCOTT: No, I think that's fine. John, any further questions for Dimitra?

MR WALSH: No thanks, Patricia.

MS SCOTT: Thank you very much. Thank you for attending today.

MS DUBROW (LIV): Thank you very much.

MS SCOTT: We look forward to getting your submission, and particularly addressing those questions. Thank you.

MS DUBROW (LIV): Thank you.

MS SCOTT: We might just have a little break now. John, we are just going to take a few minutes.

MS SCOTT: Good morning, Irene.

MS KWONG: Good morning.

MS SCOTT: John is on the Skype and he's also on the phone, so don't worry if the picture drops out.

MS KWONG: No.

MS SCOTT: We'll still be able to hear you. Thank you for coming along today and thank you also for providing some notes in advance. That's very useful. Now, we've set aside 20 minutes for your presentation.

MS KWONG: Okay.

MS SCOTT: So when you're comfortable would you like to just identify yourself for the record, and I think you're representing yourself. Is that correct?

MS KWONG: Yes, I am.

MS SCOTT: All right.

MS KWONG: And I'm not really involved with Scope because I obtained accommodation and also employment through them but I've been - this presentation is as an individual.

MS SCOTT: Thank you.

MS KWONG: My comments from the summary report set out by the Productivity Commission draft report, so I've picked out the issues that are important to me. Excuse me for reading from my notes but that's the way that you'll get it indirect format and not all jumbled around.

This summary is comprehensive, covering issues in order of priorities in the view of the commission, gathered too from public consultations. With respect, are my National Disability Insurance Scheme priorities from the review as I see them. The Productivity Commission needs to have teeth. That is to ensure that other government bodies don't abrogate their responsibilities because of the national scheme or when the national scheme is rolled out. All parties need to be working together.

Mentioning funding through taxation may put communities offside with the scheme in today's political climate due to the vote around carbon tax and the flood levy, even if it's only one option to fund the NDIS criteria for groups eligible to be considered first, and that is people with newly acquired disabilities. Older people with lifelong disabilities should be one of the first groups, given that they have lived with the drawbacks of no scheme throughout their life, being mindful of the fact that people with newly acquired disabilities may have more access to litigation, thereby obtaining funds to secure their future, more so than persons with disabilities from birth, and the fact is that some in this age bracket may well be dead before the implementation, so therefore deserve to benefit earlier.

With the media campaign - mentioned advertising, which is good but not sufficient. People with disabilities must be at the forefront of the campaign to promote and be the driving force to sell the scheme and keep the momentum going in the public arena, therefore they can tell people what this scheme means to people who have a disability. Scope Victoria already have the highly credentialled Disability Educators Group, who delivers disability awareness education to the community. Therefore, it's logical to call on a group like the DEG to deliver and promote the NDIS in their own behalf on a fee-for-service basis. It certainly would add more passion and commitment driving the message across than others do bringing the same message on our behalf.

Opportunities for people with disabilities to speak to politicians directly about the scheme when it's unfolded, to continue to support the scheme and keep the momentum and get it right, together, and I've mentioned "together" several times for the obvious reason, for the exact reason on that previous point.

MS SCOTT: Yes.

MS KWONG: No financial disadvantage should be imposed on people with disabilities who are employed or receive the Centrelink pension because of the NDIS scheme being put in place. Public transport that has better security, accessibility to trains, buses, et cetera, more staff to assist embarking and disembarking, more public awareness to ultimately save on taxi costs in some cases, but by no means in all cases, as transport would be more accessible to the whole community. This is an area where the enforcement component of the NDIS comes into play to make it happen.

The Baillieu government is working on a transport strategy now or in the near future in an attempt to achieve an improved system. The Multi Purpose Taxi Program is vital for people with disability who cannot cope with other modes of transport. I doubt the cost of the MPTP can be reduced overall, given the rate of disability and the ageing population. However, if the mobility allowance was increased under the same criteria as at present, that would mean that fares for employment, training and other gainful activities undertaken on a permanent basis wouldn't have such a negative impact on people with disabilities as is the situation now, thus leaving more disposable cash for more leisure pursuits as other citizens are entitled to do.

Maybe if there are insufficient funds in some programs, there needs to be pressure brought to bear on the federal government to curtail expenditure on non-essential programs - that is, the rollout of the national broadband program - to boost the funding allocated to the NDIS.

In conclusion, I would urge the commission not to rule out any existing programs dealt with in the summary report as they are vital to people with disabilities, otherwise they would not have been set up in the first instance. Thank you for this opportunity to express my views on this interim report.

MS SCOTT: Thank you very much. John, do you have some questions for Irene?

MR WALSH: Irene, I think your presentation has been excellent. I guess I'd like some information on how you think some of these initiatives that you talk about could best be achieved and how long it might take to get some acknowledgment within the departments that you mention.

MS KWONG: I don't quite understand where you're getting to, John. Just elaborate on what you want me to do and, if I can, I'll do that for you.

MR WALSH: I think the mobility allowance, for example: what activities do you think need to happen to achieve your objectives?

MS KWONG: If the government is more informed about where the national insurance scheme has to go and where the funds have to be allotted, maybe you can target the Centrelink programs to make sure that the mobility allowance is increased, for just the reasons that I stated. And for people that are undertaking training and employment, et cetera, if the mobility allowance was increased then they wouldn't have to pay so much in the initial stage and then they could use that money for their leisure pursuits for whatever they had to do over and above their work and skills activities during a week time.

MR WALSH: Thanks, Irene. That's great.

MS SCOTT: Irene, I don't have any questions. Thank you very much for coming along today and thank you for your submission. It's very much appreciated.

MS KWONG: Thank you very much for the opportunity.

MS SCOTT: Good morning.

MR DAWSON-SMITH (AV): Good morning.

MS SCOTT: Welcome to our hearing today. As you know, we are recording for the purposes of the transcript.

MR DAWSON-SMITH (AV): Sure.

MS SCOTT: We'd ask you to identify yourself and your organisation. We have allotted 40 minutes for your presentation.

MR DAWSON-SMITH (AV): Thank you.

MS SCOTT: And John and I are sure to ask some questions.

MR DAWSON-SMITH (AV): Excellent. Thank you.

MS SCOTT: Please proceed.

MR DAWSON-SMITH (AV): My name is Murray Dawson-Smith. I'm the chief executive officer of Autism Victoria. The presentation that I'd like to give you today is representative of our organisation and the views of our organisation. As an introduction, though, I'd like on behalf of Autism Victoria to thank the commission for the opportunity to present this response to the draft NDIS report.

Autism Victoria has been established for over 43 years and is a member based organisation with in excess of 9000 members and other networked contacts. Our role is to provide information, advice and support to families and individuals with an autism spectrum disorder and to advocate for systemic change in support of improved services to individuals on the spectrum.

The vision of Autism Victoria is for a world where every person affected by autism spectrum disorders receives adequate and appropriate early interventions, access to and support for a positive educational experience and outcomes, and appropriate funding for support to reach their full potential in adulthood. Our presentation to the Productivity Commission is based on our aim to assist the commission to develop a model that reflects the needs of individuals and families managing autism spectrum disorders.

I'd like to begin, then, by presenting a short descriptor, which is a story about Johnny. Johnny is an 11-year-old. He's non-verbal, aside from a few requests. He's unable to write. He injures himself on property if sounds distress him or when he is frustrated or hungry. Johnny has no friends. He runs away from all places and people. He's defenceless. He's unable to dress, toilet, groom, feed or wash himself. His diagnosis at two of autism stopped his party invitations and he became an inappropriate playmate for Jack and Jill. Jack and Jill's parents disappeared off the social scene. It was sad really.

This is when the costs started to mount: speech therapy, $65 per session, because he can't talk; ABA therapy, up to $180 per hour, because he can't learn by imitation; occupational therapy, $95 per session, because he has severe sensory processing disorder; psychologist, $100 per session, for behaviour modification; swimming lessons at $30 a session because he's unsafe around water; and communication aids such as iPads, iPhones, picture aids, language, et cetera.

Johnny's school does not have before or after-school care as the government does not seem to think that parents who have children at special developmental or specialist schools should be allowed to work full-time if they need or wish to and has therefore limited income for the family, which creates inequality. Holidays likewise are very difficult because Johnny has no friends to play with. He only likes to watch DVDs, like Thomas the Tank Engine, Hi-5, The Wiggles, play keyboard or look at pictures.

Johnny is excluded from mainstream holiday programs as he is a risk to himself with absconding and he cannot feed himself or talk to others. The government provides inclusion support workers in mainstream holiday programs, but not for Johnny. Because the support workers are not allowed to be attached, he is unsafe and therefore unable to participate without support. High-needs programs are good, but they're short hours, a long way from home, so tiring and costly to drive to, and he can only go once each holiday because places are booked out, with long waiting lists. Likewise, most recreational programs for people with disabilities are for people with mild disabilities, not for the challenging behaviours of Johnnies. It's very hard to occupy him 14 hours a day as he hates most toys, he has no friends, he can't communicate with his six-year-old sister and he gets bored. She obviously goes to lots of holiday programs for respite, which is lucky for her.

Johnny cannot attend any sporting programs for people with disabilities, as a paid support worker or I have to attend with him, and these workers cost $38 per hour. As a result, Johnny's sister misses out on programs where the parent has to stay there, because Johnny cannot attend because he's behaving inappropriately. Thus, because of Johnny's high needs, she is pushed aside and misses out on many things.

Weekends are long and hard because Johnny runs away at the beach, he runs away at playgrounds, he runs away at shops and he runs away at festivals. If you call him back, he doesn't respond, and he doesn't call or talk to anyone. He doesn't return when he wanders or runs off, and the strain of vigilance to keep him safe is too hard.

There have been five - and in fact most recently, on Thursday of last week, a sixth Melbourne autistic absconder - who has died since December 2007 by drowning or being in an accident.

Johnny needs his hand held everywhere outside the home, even to pay for items at the checkout, which makes it almost impossible when one only has two hands. Queues are a nightmare, as he won't stand and wait. Airports and festivals are overwhelming, with people and bustle, and there is nowhere to take him which is enclosed. This limits family recreation and social options.

So what does the future hold for little Johnny when he becomes an adult? Can he work, study? Pretty hard when he can't talk, write or understand basic concepts like numbers and colours. Where will he live when he cannot care for himself any more? Pity for him I had to have him so late in life, as many of us do. I have 34 years up on his young, fit body, and I feel it. Who will feed, toilet and dress him?

At present there are 1300 people with a disability registered for crisis supported accommodation in Victoria. We are awaiting an effective national disability insurance scheme so that Johnny and the whole family can be included as equals in society instead of being excluded, isolated and disregarded. I can obviously provide the name of the family member who wrote that, if it's required.

MS SCOTT: Thank you.

MR DAWSON-SMITH (AV): It is therefore within the context of the ode to little Johnny that Autism Victoria presents this submission. We'd like to begin by saying this is potentially a once-in-a-lifetime opportunity for a scheme to be designed and funded that will meet the needs of both individuals and families impacted on by autism spectrum disorders, and it is critical that the opportunity should not and must not be lost.

Autism Victoria acknowledges from the outset that the design of a universal support system for people with a disability is an extremely complex and challenging process. That the Productivity Commission has managed to develop a model at all is cause for celebration and we should be careful not to pass criticism of the model for criticism's sake. In saying that, it is important to note that for many individuals and families on the spectrum the challenge to access appropriate supports has been an ongoing battle for many, many years. The introduction of the NDS therefore is an opportunity for the needs of the autism community to be met in the proposed model.

It's also true that in the section on early intervention, the writers make reference to children with autism and the need for funding of early intervention services, and for this we applaud the commission, but they do not - in this report, at least - indicate what level of support this should be. That is, should the support be based on something like the 1000 hours model or something less or more? This issue is equally true for adults on the spectrum who may at times function well in society and then, in response to a sensory or other issue, become severely disabled. The NDS does not at this stage provide, in our view, an appropriate response.

There is the real possibility that through an individualised support model, driven by funding issues and market forces, there may also be the risk that it leads to a two-tiered system of support based on the notion of ability to pay and perceived value for money, with individuals with little or no family support being obliged to utilise a poorer service, while those who can top up payments will be able to access a premium model. It's particularly critical that the NDIS recognise the right of families to access what would be considered currently a premium model which is, in effect, the optimum for autism spectrum disorders.

Costings for ASD individuals within an NDIS model must recognise current research that recommends 1000 hours of early intervention per annum in the early years, as well as issues around age and equipment, such as the funding of GPS tracking systems for ASD absconders, fridge and cupboard locks, computers, iPads, trampolines, et cetera. Further support for respite, both general as well as after school and school holiday periods, must be included in the NDIS model.

I'd like to now just refer to the summary document that was prepared by the Productivity Commission and make comment on some of the specific points that were raised. Point 4 in the document talks about the functions of the NDIS, including quality assurance. I guess from Autism Victoria's point of view, we would argue that this also demands a model that ensures not only quality assurance but quality outcomes and quality service delivery.

The notion of a system based on a quality assurance is the current model, which in our view simply demands an administrative response and does not necessarily address the fundamental questions of quality service and quality outcome. It suggests a critical component of any new system should be and must be a form of accreditational licensing that assesses the quality and knowledge of the service system, the quality of service outcomes and the quality of support staff, whether via an organisation or directly employed by a person with a disability.

Point 6 goes on to talk about an advisory council of key stakeholders. It is Autism Victoria's view that it would be essential for a key stakeholder group to include an expert voice on autism spectrum disorders to ensure the scheme reflects the needs of this group. At this stage there is little confidence that the current advice is taking into account the particular issues relevant to autism spectrum disorders.

Point 8 talks about increasing choice. This of course implies that choice is able to be accessed. This raises questions and challenges within the evolution of a service delivery system, including access to skilled staff, whether part of or independent from a formal service system. Having identified the need for high-quality staff, the next question is how to achieve this within the current wage models. Pay rates within the disability sector are historically poor and, without a significant investment, the risk is that individuals will seek the lower-cost model and potentially the lowest-quality service and service outcomes.

Point 9 talks about access to specialist and mainstream services. This is an interesting comment, as it suggests that the disability service sector is somehow not mainstream or generic enough for people within the NDIS model. If, however, the suggestion is that people in the NDIS should be able to access neighbourhood houses, local schools, et cetera, then this has long been the case. In saying that, however, the major issue has been the inability of these mainstream services to meet the specific support needs of people with a disability. This is particularly true for people on the spectrum who are often not recognised as having a disability and thus are not given the level of support or assistance they require to access mainstream services.

Point 14 talks about states and obligations. Again, if this model is to be implemented, it's critical that these funding amounts are quarantined immediately or there is the potential for the states to reduce funding in anticipation of the introduction of the NDIS. The quarantining of funds would also ensure that there was no loss of employment and no loss of expertise within the state system. It would also encourage states to continue to invest at the state level, with the knowledge that the commitment will continue into the future. It's suggested it would also reward the states already heavily investing in disability services, and I cite Victoria in the case - that it currently invests some $1.4 billion into disability services, which is a significant investment and we'd like to make sure that that doesn't get lost to the system.

Point 16 talks about the implementation of the NDIS and proposes a one-year trial. I suppose our concern is: is this enough time to actually trial the model effectively and to make sure that many of the issues and the challenges are ironed out before we roll it out across the nation? We would like to think that we take the appropriate amount of time and not be locked into a specific time line but rather to get the service system right as we roll it out. We would support taking time and not setting a limit.

MS SCOTT: Would you have any idea, Mr Dawson-Smith, what that appropriate time would be?

MR DAWSON-SMITH (AV): Our experience has been that putting a model up - and we could use the Helping Children with Autism package as an example of a national rollout that happened. Over the three years that that scheme has been operating, it has been subject to fairly regular change and therefore creates confusion and concern within the recipients about what benefits are they now entitled to. We would suggest that, had that been rolled out perhaps a little more slowly and identified some of the issues in the first instance, you may have had a better system nationally by rolling out and managing the problems at a state level or a regional level first.

I think there are real challenges with a national disability insurance scheme and the concern for me would be: at the end of a 12-month period, would you really have a clear idea of where are the dangers, where are the pitfalls, and how could we address those before we roll it out across the nation? So all we would caution you is: we certainly support the notion of a slow rollout and we're very comfortable with taking the time and getting it right before it becomes a national scheme.

MS SCOTT: So if it took five years, 10 years, you'd be comfortable?

MR DAWSON-SMITH (AV):   I'd be uncomfortable with five or 10 years, but I'd certainly be comfortable with a two-year, perhaps even a two and a half year, process. I'd rather us get it right and roll it out effectively and properly than roll it out and have families distressed and being upset about a scheme that doesn't address their issues because it was rolled out too quickly.

MR WALSH: Murray, you mentioned the Helping Children with Autism plan that's been going for three years.

MR DAWSON-SMITH (AV):   Yes.

MR WALSH: Are there any lessons from that that can be used to expedite the rollout?

MR DAWSON-SMITH (AV):   Certainly we would suggest things like the provider panels that have been established, for example. We would have suggested that they should have been registered well before the rollout of the scheme, because one of the problems with the scheme was that we had people receiving entitlements but not having access to services because the services weren't yet approved. So one of the learnings would be, in our view, that if you announce and alert people to what they would need to do to become a provider within this scheme - for example, our provider panels: when we began in Victoria we had roughly 500 people register for access to services in the first three months but only had four or five provider panels able to meet their needs.

Clearly, a significant number of those people therefore would have missed out on service because there was no service to access, so we would have suggested that - again in hindsight, had we known - the answer was, "Why didn't we call for provider panels to be registered six months beforehand and make sure that they (a) met quality standards, (b) had the competency to deliver and (c) were geographically located in a way that would assist families?" Then when you start the scheme, you already have a significant number of providers available and ready to meet the needs of families. Now, that didn't happen and that was a good learning.

I think the other learning was that we didn't recognise the issues of isolation and therefore the cost for families to be able to access services. In many cases we've got people in fairly isolated areas, and because there were no providers locally and they have to drive significant distances, that becomes a cost impost on top of the cost of service delivery. So we would suggest that they're the benefits of probably registering providers well in advance.

MR WALSH: Any submission you've got on those sorts of lessons would be really valuable.

MR DAWSON-SMITH (AV):   I'm really happy to write a summary on our view of how that process has gone, and we'll provide that to you. It will probably take three to four weeks but certainly by the end of April we'll happily get something to you on the lessons we've learnt.

MS SCOTT: We appreciate it, thank you. Please proceed.

MR DAWSON-SMITH (AV):   The areas of concern for Autism Victoria - and I say concern; I don't mean criticism. I guess I'm saying concern in that we would like to think that these things are being addressed. I would acknowledge that we may well have misinterpreted some of the report. So if in fact some of these you would feel have actually been captured in the report, we apologise for bringing them up. However, from our point of view it's important we raise them and, therefore, if they are in - we apologise if they're not - we'd ask that they be considered.

I guess part of our concern is the need to get a clear definition of severe or profound disability. From our point of view these terms appear to be driven by the intellectual and physical disability community and do not necessarily recognise the unique needs of individuals with an ASD that we would consider is a severe or a profound impact on their lives, which wouldn't necessarily be captured in the traditional sense of a severe or profound disability.

The other part to that is we'd ask that the adoption of relevant assessment tools should include things like the DSM-IV to ensure individuals with an autism spectrum have effective and well-recognised assessment tools, and I have in fact provided today a list of recommended core assessment battery for autism spectrum disorders which we will attach to this report. It's a significant number of them that haven't been identified in the report to date, which is fine - we understand you're not going to put everything in - but we thought it would be valuable if we put in all of the tools that are currently being used to assess autism spectrum disorders from early childhood up to adulthood, which are sometimes quite different tools.

We would suggest that there is a requirement, if not for specialist case managers, certainly to ensure that all case managers are very familiar with autism spectrum disorders. The experience in Victoria has been that state government has recognised the lack of knowledge by case managers and in fact has funded Autism Victoria to undertake some training across the state of case managers because there is an acknowledgment within the case management system that they aren't familiar with nor knowledgable around autism spectrum disorders and the impact that has on behaviours.

So we have conducted training now across the state. We've done training for probably 1200 case managers, but of course they keep moving on and then you get new case managers who again don't have the training or the experience in managing people with a spectrum. So again the risk is that they will misinterpret the need and misinterpret the amount of support that an individual needs, just through lack of knowledge, not through intent. We would also suggest that the NDIS will need to support and enhance the capacity of the service system to meet the needs of individuals in rural and remote locations.

There's also our concern that workforce development we think will potentially be of greater importance as the current formal support system moves from the structured model to a less formal and less structured model. There are real concerns, from our point of view, that there will be significant numbers of people out there now who will seek, if you like, the willingness of people to work below a particular wage scale, and therefore will they have the competency and the skills? That will be driven by people's needs to stretch their support hours as far as possible. We understand that, but it's then about will the scheme in fact protect people from picking poor options, if that makes sense.

There is an issue, we think, around the workforce and that's clearly an ageing workforce as well. Ours is a workforce that's dominated by women. It's a workforce that's going to put people in high-risk situations going into personal homes. We think there's a number of OH and S issues around a national disability insurance scheme that aren't necessarily the responsibility of the scheme but need to be worked on in company with the scheme.

The NDIS should support staffing models that do not encourage the growth of a casualised workforce. Given that there is a current trend particularly - I can only talk from Victoria - towards a casual workforce, our concern is that the more individualised model will create even less sustainable employment and eventually a less-skilled workforce as job security is lost. The aim of providing choice must also come with a model that addresses quality. In particular, it's important that specialist areas such as autism have a service structure that ensures services being delivered, whether by an organisation, do meet particular standards.

MS SCOTT: Mr Dawson-Smith, can I just pull you up there just to clarify something?

MR DAWSON-SMITH (AV): Sure.

MS SCOTT: Why would job security be lost?

MR DAWSON-SMITH (AV): The history of disability services in Victoria has been that as you move into individualised programming and therefore you provide people with choice - and I think everyone absolutely endorses the notion of choice. The problem with that then is as an employer do I employ people on a permanent basis when the person who's paying for that support says, "Well, I don't like that worker any longer. I'm going to somebody else"?

As an employer I now employ you casually, and I employ you on the basis that as long as this person with the individual support plan wants you as a worker, then you've got a job. But if that person has a fight with the support worker, doesn't agree with the support worker and says, "I don't want to work with you any longer. I'm now going from Yooralla to Scope," that worker is now out of a job because I don't have a capacity to pay them because they're only paid because this person is providing a support package from me.

MS SCOTT: How is that different to consumers exercising choice in other areas like doctors?

MR DAWSON-SMITH (AV): It's certainly not different. The concern is, though, that we have built up a skilled workforce built around continuity of employment and security of employment and so historically the disability sector - and again I'm talking Victoria, I'm not talking about the rest of the country. But in Victoria we got block funding and so you knew that you were going to get X amount of dollars per year to deliver support to Y number of clients.

MS SCOTT: And that includes your organisation?

MR DAWSON-SMITH (AV): No, we actually don't do that, so this is not an issue for us.

MS SCOTT: So this is about other organisations?

MR DAWSON-SMITH (AV): This is a twofold issue. One of the concerns from our point of view is that as an individual who's now going to get an individualised package - now, they can choose to do that through a service system, we understand that, in this model.

MS SCOTT: Right.

MR DAWSON-SMITH (AV): The question is, though, when you individualise the service system you also individualise the employment relationship between that individual and the employee.

MS SCOTT: Not necessarily.

MR DAWSON-SMITH (AV): No, so we're saying where that person becomes an individual and wants to run their own service system, sorry.

MS SCOTT: Yes.

MR DAWSON-SMITH (AV): And so the concern for us is that even if I as an organisation have a relationship with person A, who has an individual package, they come to me as a service provider and they say, "Mr Service Provider, we would like you to provide support in my home," and I say, "Fine. I will now arrange for somebody to go into your home," I now enter into an employment agreement with that individual, not the person with a disability. The problem is because I am now only going to have that happen if this person gives me the money, I don't enter into a permanent contract agreement with that employee. That employee will be casually employed because I can't guarantee, beyond the money that's being brought in and passed over, an employment relationship.

MS SCOTT: I'm just trying to reconcile that with all the other things, the other services that a person may have. I mean, hospitals don't know exactly the number of people they're going to get the next day, but they employ people in - - -

MR DAWSON-SMITH (AV): Hospitals are bulk-funded, though. Hospitals are funded by government to be available to provide services.

MS SCOTT: In Victoria I understood they were actually case-funded.

MR DAWSON-SMITH (AV): Well, they are. Yes, that's true.

MS SCOTT: Right, okay. So let's pick a doctor's surgery - I mean, just something that's not too - - -

MR DAWSON-SMITH (AV): Yes.

MS SCOTT: A doctor can't know with complete accuracy the number of people that are going to ring up on a Friday or a Wednesday.

MR DAWSON-SMITH (AV): No, that's true.

MS SCOTT: They still have permanent staff.

MR DAWSON-SMITH (AV): Absolutely.

MS SCOTT: And David Jones has permanent staff. They don't know exactly the number of dresses they're going to sell on a Wednesday or Thursday.

MR DAWSON-SMITH (AV): No, they don't.

MS SCOTT: They may have casualised staff but they also have permanent staff. I'm just trying to work out why, in a sector that you acknowledge is underfunded and there's a shortage of trained personnel in some areas - why suddenly people would find that permanent jobs disappear and they're going to be offered casual positions. The logic we've got in chapter 13 on the workforce is that with increased funding in this sector there will be a greater opportunity for workers to think about where they want to work and how they want to work. This will be a growing area in the market that people will have more choice, and in fact that employers will want to get the best workers they can, be most attractive to their clients and so on. I guess what I'm trying to work out is why the disability sector is going to head off in a different direction from other things that we are more familiar with.

MR DAWSON-SMITH (AV): I'm happy to answer that question. I think the difference is that within the commercial or retail sector, I as a commercial operator employ two forms of worker. I employ a small permanent workforce and I employ, potentially, a more significant casual workforce.

MS SCOTT: Or it might be the other way around.

MR DAWSON-SMITH (AV): Or the other way around. But the reality with that is that I actually set the price and I set the profit margin that I can make, based on the desire for the employment model that I wish to operate. So if you give me freedom to set the prices for my services and the marketplace is happy to pay that, then yes, as a disability sector I'm going to have to learn a whole new set of skills, and that is how to run a commercial enterprise in a commercial model, but for me as a commercial enterprise, as long as I can say to Joe Bloggs when he walks through the door, "You may well be getting" - and I think you used the word a "reasonable" price. I'm not sure of the exact words you use in your report, but you're actually going to be setting a rate, as I understand it, or at least the intent at the moment is to set a rate.

The dilemma with that is that I am then sitting there saying, "Then that's not necessarily what the market is asking me to now do if I want to employ permanent staff." It may well be that if I'm getting a system that says, "We will pay you $45 an hour for support," if the marketplace is saying, "If you want to employ me as a worker and permanently, you're going to have to pay $50 an hour," and you allow me to charge the consumer $50, then that's fine, but if I'm not allowed to charge the consumer $50 because a market rate has been set by an external body, then I am going to have trouble with my employment schemes. There's no question I will.

We've seen that within the disability sector in Victoria. The casualisation of the workforce here has been quite profound and quite noticeable. So, for me, the differences between a retail sector - I can set profits and I can raise the price of my goods to make my model of employment whatever model I like, but that's because I have that flexibility. If you give me that flexibility under an NDIS then certainly I think you're right, I think you can have that, but the examples in Victoria have been that there's a number of commercial services that have come into the system and those commercial services have certainly dropped the wage rate of workers and have certainly dropped the expectation of skill sets of workers. Will the marketplace address that? I sincerely hope that it will, but at the moment it is a concern from our point of view.

MS SCOTT: Thank you.

MR DAWSON-SMITH (AV): I go on to say that the funding regime should not be limited by a unit price that restricts the service system from developing new and innovative services. We'd like to think that an NDIS bureaucracy would remain hands-off and not tie up the system with regulations in a way that restricts the ability of services to meet the needs of individuals.

Within the examples provided of current impairments of body function, many of the issues facing individuals with an autism spectrum disorder are not captured. These areas include danger perception, communication as distinct from language, indifference to auditory stimuli, sensory processing, understanding concepts of norms and social mores, temperature regulation, et cetera. Likewise, when reference is made in part 2 of the report to activity limitations and participation restrictions, there's no mention of absconding, obsessions, patterns of behaviour, of injury to self or others.

There is a critical need for a national register to identify and plan for service provision. Given the unique nature of ASDs, any advisory body must contain specialist knowledge as a priority. I think we've mentioned that before; I apologise. It will be important to develop appropriate principles for adoption of evidence based therapies across the disability sector. And again, as I say, I do have an attachment here that we would simply put to that, around current assessment tools.

MS SCOTT: Okay. Thank you. You have concern about, I think, the eligibility criteria and I wouldn't mind going to that item if we can.

MR DAWSON-SMITH (AV): Sure.

MS SCOTT: Is that okay, John, to go - - -

MR WALSH: Yes, sure, Patricia.

MS SCOTT: I don't think you've got a copy of the overview with you, so I might provide you with mine.

MR DAWSON-SMITH (AV): Thank you.

MS SCOTT: I think in your text you refer to concern about the use of "severe" and "profound", but actually in the eligibility criteria that I draw your attention to, we don't use those terminologies. In fact, quite a bit of the text goes on to explain why we don't. I'll just find you the right page; I think I've opened it at the right page for you. So, John, I'm just going to the eligibility criteria on page 13 of the overview.

A person getting funded support from the NDIS would have a permanent disability or, if not permanent, expected to require very costly disability supports, and would meet one of the following conditions, and then we have "significant limitations in communications, mobility or self-care". I think Johnny could well fit into that category, the way you've described him.

MR DAWSON-SMITH (AV): Sure.

MS SCOTT: And then "have an intellectual disability, be in early intervention group" and that's where we do specifically mention autism, acquired brain injury, cerebral - - -

MR DAWSON-SMITH (AV): That's correct - cerebral palsy.

MS SCOTT: That's right. But that doesn't mean that those people are only, of course, in that group.

MR DAWSON-SMITH (AV): I appreciate that.

MS SCOTT: "And have identifiable benefits". So this is sort of like a catch-all. When you comment on the eligibility criteria, while we did use "severe" and "profound" in the issues paper because that was in our terms of reference, you might want to have a look at this page, page 13, in terms of your commentary on that, because I think you might find it more comforting than - you know, probably concerns that you had about the issues paper. If it's all right with you, I want to just go through two areas.

MR DAWSON-SMITH (AV): Yes.

MS SCOTT: You talk about a two-tiered system. Do you think that a two-tiered system exists now?

MR DAWSON-SMITH (AV): I think historically our system has been - and, look, I'm talking Victoria, so I'm not talking anywhere else here.

MS SCOTT: Sure.

MR DAWSON-SMITH (AV): In Victoria particularly, our system has historically been that you go into the service system, that is a system operated by a registered organisation, it's funded out of unit price to deliver, it operates within that unit price model and everybody effectively gets that unit price service standard. In the last three to five years we've actually introduced commercial operators into the marketplace as well - not many of them, but a small number.

That small number have entered into the marketplace and are now providing similar services but at a significantly lower wage rate for its workforce, and the challenge with that is - again, coming back to that individual model - if I've got $10,000 of support and I can buy $10,000 of support from one person or from one group at $25 an hour, it means I'm going to get X hours. If I can buy it from another group at $15 an hour, I get X-plus hours. The concern for us is not that they should have the right to buy it and get X-plus hours, but it's: are they getting X-plus hours of support or are they getting X-plus hours of care? What they are actually getting is the concern for us - not the price per se but, rather, the quality of the service that's being delivered.

So the issue for us is: if you end up in that model, do you then oblige people to look for - and I've used two-tiered. Historically, we would talk about a Target model against a David Jones, because my need is to expand the numbers of hours of support, and am I actually getting support now or am I actually simply getting care? Now, that may be okay if the family and the individual understand what they're getting, but if they don't understand what they're getting and have an expectation of something different then that would be a concern from our point of view.

For example, within the autism spectrum community, if I'm spending $15 an hour and I'm not getting someone with a knowledge of autism, what level of support do I truly get from that dollar-cents value? And if an individual is unable to advocate for themselves, what we're looking for then is a system that will ensure that they get the level of support that they should be entitled to.

MS SCOTT: Does your organisation see that the disability support organisations - I don't know if you're familiar with that concept that we've put in here.

MR DAWSON-SMITH (AV): Yes, I've noticed that in your reports.

MS SCOTT: All right. Would that be a role that Autism Victoria would see itself playing if this scheme got up? For example, playing the role of being able to be in the person's corner advising the individual or their family about services available?

MR DAWSON-SMITH (AV): It certainly is a view that we've got. We've also recently developed an accreditation system which we think - I'm not promoting that here, but I'm saying that we think that's the kind of thing that should be in place. Whether it's ours or somebody else's is not the issue. But I have real concerns that we run the risk of a system where people, for a range of reasons, may well be exposed to risk.

MS SCOTT: Okay. You also elsewhere in your paper seem to use this idea of a two-tier system in two senses. One that I think I've understood you to say now is that people unwittingly think they're getting a superior David Jones service but in fact they're getting a Target service and they don't realise.

MR DAWSON-SMITH (AV): That's correct.

MS SCOTT: Okay, so I think I've got that, but I think you also refer in another part of your paper to the idea that some families, because they've got greater means, may actually be able to top up as well.

MR DAWSON-SMITH (AV): That's correct.

MS SCOTT: So what would you like the commission to think about in relation to the capacity of people to top up? Would you like that to be legal? What would you like to see happen there?

MR DAWSON-SMITH (AV): No, not at all. I think people have the right to purchase additional services and supports if that's what they wish. I guess the concern is to make sure, though, that people are being adequately funded in the first instance if there's no requirement to have to do the top-up. I say top-up for basic services. I'm not talking about top-ups for additionals.

We know that there are people in the residential sector, for example, that are in a residential unit that's being charged such significant amounts of money that there is no disposable income for that individual. We would suggest that that's forcing people into a top-up model that shouldn't be happening. There are other circumstances where an individual may have disposable income but the family have given him extra money to do other activities as well. We would suggest that that's a decision for the individual, but it shouldn't be a system where a family is obliged to top up, nor should it be a system, in our view, to get the basic services.

The residential sector is a good example, where you'll have people in one residential unit that are paying 25 per cent of their pension and their Commonwealth rent assistance and that's their total outlay. In another residential setting, another residential home of equal service and equal size, they will be paying that plus telephone, plus electricity, plus property repairs, plus unit maintenance, which means that at the end of the day their disposable income is non-existent. That, to me, is a real concern.

MS SCOTT: John, do you have any questions for Mr Dawson-Smith?

MR WALSH: I think the one about an intermediary, a disability support organisation, is important in this context. But I have some questions around the issue of the 1000 hours per year question. You say at the bottom that there's an urgent need for a national register. I wondered if you had any information on the distribution of needs. So in a particular year of births - say there are about 300,000 children born in Australia every year and X number of them have autism - do you know the severity distribution of those children? Like, do 20 of them need the 1000 hours?

MR DAWSON-SMITH (AV): At the moment, the most recent formal statistics would say that it's one in 160. In saying that it's one in 160, I need to just caution that the Olga Tennison Autism Research Centre at La Trobe University has recently been doing its own research and they now suggest the numbers are closer to one in 100 to one in 110. So of the 300,000 children that are born every year, approximately 3000 of those, in theory, will have autism.

MR WALSH: But how many of them will need 5000 hours a year, 1000 a years, 50 hours a year?

MR DAWSON-SMITH (AV): The suggestion has been that the 1000 Hours campaign - which is an early intervention model - that all children on the autism spectrum, if they are given the 1000 Hours interventions, the benefits of that are significant long term, that in life terms they make a profound difference to the wellbeing and the ability of those children to access mainstream schools, to avoid any other support needs throughout their lives.

MR WALSH: How long would that intervention need to go on for?

MR DAWSON-SMITH (AV): Again, because it's a spectrum, that intervention for some children may be for only one year. For other children it may be for three or four years. I won't mention people that I know, but there are people who would be getting 1000 hours of work and would see significant improvements in their child in a year. There are others who would need to take three to four years to see the same improvement. Ultimately, as a cost-effective strategy it is by far the most cost-effective method to avoid long-term obligations on a national disability scheme, for example, to provide lifetime support.

MR WALSH: Any information on that in more detail would be very useful.

MR DAWSON-SMITH (AV): Yes, I'm happy to put that in, along with the comment on our learnings from the Helping Children package as well. We'll give you a kind of double-edger, if you like.

MS SCOTT: That would be useful. John, any further questions?

MR WALSH: No. Thanks, Murray.

MS SCOTT: All right. Thank you very much, Mr Dawson-Smith.

MR DAWSON-SMITH (AV): Thank you. Could I just say that I really do appreciate the opportunity to speak today and I'd like to thank the commission particularly for the work it's done and, I guess, for the challenges that are ahead, good luck.

MS SCOTT: Thank you.

MR DAWSON-SMITH (AV): Thank you.

MS SCOTT: Welcome to our hearing. As you can see, we're recording the testimony for the transcript. It will go up on the web site. So don't be worried about the audience. There's a bigger audience out there. Of course, John is on the telephone, who's the associate commissioner, and from time to time he'll appear on the screen, depending upon the technology.

MR WALSH: Hi, Megan. Hi, Mary. Sorry I'm not there at the moment.

MS ATKINS (IP): That's okay.

MS NOLAN (IP): That's all right.

MS SCOTT: Would you like to identify yourself for the transcript and make an opening statement. You can anticipate that John and I will want to ask you a few questions.

MS ATKINS (IP): Certainly.

MS SCOTT: We've got till lunchtime at 12.30, so you've got your full half-hour.

MS ATKINS (IP): Thank you.

MS SCOTT: Plus a few minutes extra.

MS ATKINS (IP): Great.

MS SCOTT: So off you go.

MS ATKINS (IP): Good afternoon. My name is Megan Atkins. I'm co-founder, secretary and treasurer of Inability Possability. It's a volunteer role I've held for the past 10 years. My day job is as an exhibition designer at the State Library here in Melbourne. Mary?

MS NOLAN (IP): I'm also a co-founder of Inability Possability, and a member of the Young People in Nursing Homes Consortium, co-founder of that. I got into this world - I'm the mother of Chris Nolan, who had a catastrophic brain injury in 1996. He hears and understands but can't speak or see or move and is far from being a passive recipient. He's an engaged citizen really and is living evidence of something that's working.

MS SCOTT: Good. Thank you.

MS ATKINS (IP): I might just go over Inability Possability. We're a volunteer organisation. We have five members. We formed to seek to address situations of disadvantage experienced by young people with acquired brain injury who require high levels of care. These young people are amongst the most vulnerable in our community and, due to the nature of their acquired disabilities, they're often powerless to challenge structures that keep them in their position of disadvantage. However, given appropriate environments, resources and care they can continue to make significant improvements for many years and actively participate as interdependent members of community and society.

In November 2002 a family and friends association was formed. We found a real need, that people didn't have anywhere to go. So it includes young people who live in nursing homes, who are cared for at home - often by ageing parents - or who are awaiting replacement in an acute care facility. We have contact with over 80 people, including 30 young people with severe ABI.

We've also worked with and supported the What Does Chris Want group, which formed in 2004, in particular publishing the model that I've just given you - "(ABI): A socio-medical model for the care of young people with severe acquired brain injury". It was launched by Bill Shorten in 2008. Mary, and also Rosalie Hudson, on behalf of this group have made a submission to the commission, which is number 579.

We'd just like to really thank you for the opportunity to respond to the draft document and present today. It really means a lot to us and the people we represent, who are often non-verbal and cannot speak for themselves, and the massive amount of work that's gone into the draft report - like, it's quite an extraordinary document and we see it as a really positive document, so thank you to everyone for the work on that. The points raised in our submissions have been referenced in particular to giving power and choice in decision-making to people and the issue of ageing carers.

We've looked at the draft report through our experience and a prism of those young people with severe ABI, who are often hypoxic with high needs, and they have a narrow margin of health. They're usually non-compensable. So we're focusing directly on raising points and asking questions in relation to this group who, as I said, are generally non-verbal. We do recognise that this is an insurance scheme but also that the consumers are people. We have seven key points to address, some of which are questions, and we obviously don't expect full answers today but we wanted to raise them because they point to key issues for us and the people we represent.

Our first point is in regard to 16.3 and 16.6 in the report, referencing state based schemes. In the NIIS the meanings of "injury" and "accident" are unclear to us. We were just wanting to know will the NIIS cover all people with an ABI who have a catastrophic brain injury, regardless of the cause and the future, so particularly hypoxic brain injury from seizure, hyperglycaemia, drug overdose and stroke? And if not, then how will the NDIS support the people who would not be covered in future by the NIIS?

MS SCOTT: Would you like us to discuss these as we go?

MS ATKINS (IP): If that suits, yes, I'm happy to.

MS SCOTT: John, do you want to just - - -

MR WALSH: Yes, Patricia. Mary and Megan, I think the response is that no, they wouldn't be covered by the NIIS. The notion is traumatic brain injury, or at least the current costings have tried to add up traumatic brain injury. Hypoxic brain injury under the NDIS - you know, I think there's no disadvantage there in terms of the intention of the availability of support. The only reason why traumatic brain injury was under the NIIS was because there are existing compensation authorities and legislation available to cover traumatic injury.

MS ATKINS (IP): Right. Thank you.

MS SCOTT: I might add to that that we're also conscious that where existing schemes operate and are operating well and they have good funding mechanisms, is it wise to recommend the abolition of those when the NDIS will be large and clearly it imposes quite considerable fiscal costs. So there are practical, legislative and funding reasons and good economic reasons for having, we think, two schemes. But we are open to suggestions and we heard this morning from one party that suggested that we shouldn't have two schemes, we should have one, so I'm just - but that's, I think, a good answer to that question.

MS ATKINS (IP): Okay.

MS SCOTT: So would you like to now go on to your second one?

MS ATKINS (IP): Sure. We understand that the NDIS will cover those with existing catastrophic injury, which is fantastic. We're wondering how is it envisaged that the existing disability system and the NDIS will interact for these people. We're concerned that there may be a funding shortfall because of the high-care support needs of this group financially, as they have previously fallen through the cracks between disability and health, so that's quite a concern for us and we're just wondering how that might be addressed in the new system.

MR WALSH: The costing for the new system has been as close as we can come to estimating the support need of people with a major disability. That costing has included the sorts of brain injuries that you're talking about. So on the prevalence side we haven't excluded in the costing people who previously had a brain injury and might or might not have been covered by one of the injury schemes.

MS ATKINS (IP): Right, okay.

MR WALSH: Prevalence model - and those people are included in the costing.

MS ATKINS (IP): Okay, thank you. Our next point is how will people with previously acquired catastrophic brain injury be treated within the NDIS, and you've actually just referred to the funding issue with that. Our concern is that there's no mention of rehabilitation services in this draft report as a service type encompassing physiotherapy, occupational therapy and speech therapy, some of which are required over a lifetime for some young people with high medical and support needs, to enable them to be free from pain, their health, wellbeing and participation in community. We ask that rehab be mentioned as a service type in the NDIS and also that people with ABI be mentioned in the NDIS as those requiring early intervention.

MS SCOTT: I actually think they may have that now. It might have been - yes, it is. I'll just show you so you can take some comfort in it. It's page 13, early intervention and acquired brain injury.

MS ATKINS (IP): Great, that's fantastic, yes. Thank you.

MS SCOTT: John, I think we can answer that little question there now. Just on rehab, John, there's always the danger that we're going to give a different answer but let's just see how we go. I understood rehab in many states is effectively within the health system as it is, so the question is we are proposing - in the draft report - there be a series of protocols to draw attention to the need for people not to fall between the gaps. This is already an expensive proposal. If you end up taking on all of rehabilitation within the scheme, where does that leave the health system and where does that then take the cost of the scheme?

So if your concern is that early intervention wasn't mentioned - and I've now shown you that it was - does that then allay your concern about rehab? You can understand why we weren't terribly keen to include all of rehab. Does that now meet your concern?

MS NOLAN (IP): No, not really.

MS SCOTT: Okay. So let's explore that a bit more.

MS NOLAN (IP): Yes. Rehab within the health system generally means six months, maybe 12 months, and then finish, and that's often enough for traumatic brain injury. However, for hypoxic brain injury - and you'd be familiar with the ABI Slow to Recover program in Victoria?

MS SCOTT: I'm aware of it but very - - -

MS NOLAN (IP): Okay. The ABI Slow to Recover program, which is state funded - Chris was one of the first to be funded under that and originally they were going to limit it at two years. That shows you where we've come with brain injury since 1996. But for people like Chris - there's a very small number, it's not a big number, but a very small number who - we call it a rehabilitative approach, so you still need that intervention. Chris is still making gains and he's also - even for pressure areas, for chest management, for - you know, often if they're unwell they will go into a particular contracture spasm, stuff like that. It's envisaged - and we'll come to that a little bit further on - that the rehab - the therapists actually train the carers, so it doesn't need a high one-to-one but it certainly needs equipment - - -

MS ATKINS (IP): Over a long period of time.

MS NOLAN (IP): - - - over a long period of time.

MS ATKINS (IP): Because people often see rehab, as Mary said, of six to 12 to 18 months and then you are better and you can go on, whereas this particular group of people, it's pretty much lifelong.

MS SCOTT: Yes, all right. John, do you have a response on that issue?

MR WALSH: Yes, I'll have a go. This is, as you guys would be aware, an extremely difficult and debatable area. I think the intention of the scheme is that therapy would be supported as long as there was an evidence base providing a good outcome. How you get that evidence base is problematic. You probably remember, back in the 80s, the number of arousal therapies that were going around various places, which really had lots of issues. In some cases they provided good outcomes, but in some cases they provided - - -

MS SCOTT: Yes.

MR WALSH: There's a need to balance the evidence. If there is good evidence, I think the scheme has within it scope for those therapies on an ongoing basis.

MS NOLAN (IP): The scheme has - sorry I didn't catch that. The capacity for that, did you say?

MR WALSH: Scope within its protocols - - -

MS NOLAN (IP): Scope.

MR WALSH: - - - to provide ongoing therapies, as long as there's evidence of continued good outcomes.

MS NOLAN (IP): I suppose one of the issues for this group of people is that they are - Chris is one of the earlier survivors, and we don't have a lot of evidence, but certainly in his case and other cases, the ABI Slow to Recover would - yes, sorry.

MS ATKINS (IP): The ABI Slow to Recover program could provide documentation on success.

MR WALSH: If you can give us some documentation, that would be very helpful.

MS ATKINS (IP): Okay. We'll gather as much as we can.

MR WALSH: Especially on the levels and the nature of therapy that are recommended, because again you'll remember back to the 80s.

MS NOLAN (IP): Yes, I remember.

MS SCOTT: Thank you. Are we up to, now, (c)?

MS ATKINS (IP): Yes. We'll probably go on to point 4. Sorry, we've revised it a little since we - - -

MS SCOTT: All right. Please do.

MS NOLAN (IP): Our experience with this group of young people with high needs indicates a socio-medical partnership model. It's an integrated program and a rehabilitative approach and it has been very successful. This has used residential aged care generally as the core base care and funding, with individualised funding from Disability Services. The needs of this particular group have not been met in disability accommodation.

The mid-term review of the COAG initiative points to a need for health, disability, aged care and rehab to come together to address the needs of this small group with very high needs. It's argued there that supporting people with ABI requires harnessing the interface between the sectors and identifies this as a key challenge for the program. They go on to argue that the program should place people with ABI and their families inside of, and with clear access to, the health and rehab systems and specialist frameworks.

I've been a member of the My Future My Choice reference group for the Victorian rollout. I think it's been obvious that the needs of this particular very small group have not been met in this initiative.

MS SCOTT: Can I just then inquire, because we are looking for successful examples of where protocols or bringing people together work: I appreciate what you're saying is things haven't worked well in the past, but now that you've had a little bit of this initiative under way for a little while, are there signs of progress, signs of hope and so on, and do you think that John and I should have faith in the capacity of protocols to make a difference?

MS NOLAN (IP): That's a big one.

MS ATKINS: Shall I take that?

MS NOLAN (IP): I think for some people who have been in nursing homes it's been terrific. They've moved out very happily. You might be aware that they categorise them into four bands. They expected that the bands would be more or less equal; I think they were low, medium, high, very high. Now, it's the very high group that really has not been moved out. There is one 10-person place here in Victoria, where we've decided that Chris would be much worse off for a variety of reasons, one of which is it's block-funded. Two, I don't think Disability - and I think some people at higher levels would admit that they don't really do that nursing care model very well. For Chris we are looking at probably him staying now in aged care, and we've agreed that with Disability in Victoria, to have perhaps a specialist small unit within aged care.

MS SCOTT: Yes.

MS NOLAN (IP): Because they are about the only ones that have got that level of expertise, but I'm not saying just your ordinary aged care.

MS SCOTT: No.

MS NOLAN (IP): It needs to be people who particularly are interested. So Chris has his base-level - I'm just using him as an example - aged care. We've been in two nursing homes now and we agreed, before we went there, that that partnership philosophy and practice would permeate everything. He then has his carers coming each day, because they just simply don't have enough time.

MS SCOTT: No.

MS NOLAN (IP): And that's covered under the individualised package; so all of his other services are covered by that. I think it has worked very well for the core staff at both nursing homes, who have become much more skilled over time. The whole team works together with family and friends, and Chris is very well connected.

MS ATKINS: I think the issue is, too, for again that very high-level needs group, which is also a small number, if their health needs aren't met they have a real risk of dying. As Mary said, the only place that we have found that's worked for this group of people has been particular residential aged care which can provide that high level of nursing and then, on top of that, the state based rehabilitation services.

MR WALSH: Mary, in terms of the residential aged care facilities, do they still get funded under the Commonwealth aged care subsidies?

MS NOLAN (IP): Yes.

MR WALSH: Okay.

MS NOLAN (IP): So they're still funded. See, under the Young People in Residential Aged Care initiative, we know now the My Future My Choice in Victoria gave enhancement packages to some people, and that made a big difference to people who chose to remain or for whom there was no other option. That covers equipment, extra therapies - a variety of services. So I think we would be arguing for this in the future.

I'm not sure whether you are aware that Victoria has about 6000 state aged care beds and they have, or did have, policy for people with specialised needs, so they are familiar with having a dementia unit or a whatever unit - palliative care unit - and I think that this could be a natural progression. A lot of those aged care beds are in country areas and regional, so that could give young people the opportunity to live close to home.

MS SCOTT: Yes.

MS ATKINS (IP): One of the issues we've found with people in our family and friends association is that they've actually had to move to the city from regional areas within Victoria to access appropriate care, which puts a lot of pressure on families and their budgets and all that sort of thing.

MS NOLAN (IP): I think if you put that rehabilitative approach in there - because you never know what they're going to get to. Chris is eating again now - not fully, but is going on to a second meal a day - and that's got hard evidence; video fluoroscopies. I mean, we haven't got it written up or anything, but - - -

MS ATKINS (IP): We're working on it.

MS NOLAN (IP): It's possible for others, we know that. I think that's one way. I'm not saying it's the only way but it's certainly a way that we'll be pursuing.

MS ATKINS (IP): The report that we've given you outlines how the socio-medical model and approach can work. So we'd highly recommend that as a model for the commission to look at.

MS NOLAN (IP): It means a big change in attitude, I think, for many people. We've found some people aren't willing to work in a partnership. Therapists like to come in, do their bit and leave, where our therapists have been with us for many years, most of them, and so have the carers, varying from six months to 13 years.

MS SCOTT: Yes, very interesting. All right. Thank you. I think we're just up to 5 or just before 5.

MS ATKINS (IP): Yes. We'll go on to point 5. We just wanted to raise: is the commission aware that the national disability standards do not include standards for health and rehabilitation? We think this would be very important to address for any cross-system integrated approaches. Just as an example, language is not common across the systems and remains, in our experience, a major barrier, but it's the disability standards not including health and rehab that have raised concerns for us.

MS SCOTT: This might be too hard to do in a short period of time, but tell me - I've decided that the disability sector is very language-orientated. I've come across all sorts of interesting issues with language. Could you just briefly explain how language could end up being a key barrier, because I'd like to think that after about 10 minutes people would get on the same wavelength, but just tell me from your experience - if you can, if you can illustrate it briefly - how it makes a difference, not just a perception of concern but a real difference.

MS ATKINS (IP): I might let Mary take that one.

MS NOLAN (IP): I've got a key example from the My Future My Choice. We raised this and so the department set up a health disability working group around the issue of discharge from acute, and that identified this whole area as being very difficult. That would be worth you - - -

MS SCOTT: Having a look at?

MS NOLAN (IP): Yes, having a look at.

MS ATKINS (IP): We can give that to you, yes.

MS SCOTT: If you could give us a reference, that would be appreciated. If it's a case of reading something further and getting on top of it, that's fine. I don't want to use up your valuable time on that now. Okay, let's then proceed with the rest of your presentation.

MS ATKINS (IP): Yes. We just have two points left. Again, point 6, we're looking at intersection with the health system. Again the great philosophical and practical differences between the sectors and the now experience with our family and friends association, it's exacerbated by the state and federal barriers which we hope that maybe the NDIS can overcome. But we're referring to point 3.19, 21 and 22 in the report. We just want to put to you how is it envisaged that this integration can be facilitated, structured and monitored well? Just from our experience it's brought many problems and issues to the group that we represent, and that may be something that you probably can't answer straightaway, but we'd just like to raise that point.

MS SCOTT: You make the points well. John, I don't know if you want to come in here.

MR WALSH: One of the undertones of this is about the intersection between the health system for long-term recovery and the disability system and where the disability system should kick in. I suspect it's also on the intersection between where medical therapy starts. So that's an issue on which any information you've got would be useful.

MS SCOTT: I think it's not too dissimilar in some ways to what you were saying, Mary, before about you can have everything written down on paper but if a therapist is not particularly interested in working in a team approach or people aren't amenable to changes or thinking about different ways of doing things, you're working against the grain. As an organisation, the commission sees the need for protocols between people and that's why I was interested in your experience. The words on the paper have to obviously translate into real actions. I imagine there will still be the need for very strong advocacy for the individuals where they are able to express their views and, for the disability support organisations, something that the commission is recommending, that there is someone always in your corner. Everyone would like to think that their loved ones are in their corner, of course, but that may not be the case in all circumstances or over time.

We're not imagining that things are going to be perfect but protocol arrangements, if you have the right attitudes, I think can see improvements, but I take the point that Mary is making. It's the aptitude and the attitude of the individuals that's probably more dominant. It's amazing that in a crisis, in Australia, some of the services that are often seen as bureaucratic suddenly find new flexibility and are able to get things done very quickly but are not able to do that in a non-crisis situation. So I guess this is very much about making improvements on where we are, but no-one I think hopefully would be naive enough to think that it's necessarily the recipe for nirvana.

MS ATKINS (IP): No, and it's probably a broader approach too. There's a great section in the draft report about the training of people and that could even go back into university. It would probably take another 10 or 20 years but if that approach is sort of inbuilt into when these people - you know, physios and everyone - are trained, I know that's a very, very long-term goal but that could be something to look at as part of that training chapter in the report.

MS SCOTT: All right.

MS NOLAN (IP): We've had such a paradigm shift in the last 14 years for brain injury - the explosion of neuroscience - but the attitudes are still very much there, I think, that this group of people perhaps isn't there or isn't functioning. I remember a therapist we had working with Chris for almost 12 months and I couldn't work out why she didn't work well with him. One of his friends was there one day and she said to me, "Get rid of her. She's not his type." And that's easier said than done. She left at the end of that year but she said to me in the last interview - I'd given her a video of Chris at home and she said, "I didn't know he was there."

So that is really important with this group, because the only way that they're going to be able to relate with you is if you give them something to relate to. So we're on the frontiers here with this group.

MS SCOTT: I appreciate that. Let's go on to your last point now because I think this is one we should discuss.

MS ATKINS (IP): Yes.

MS NOLAN (IP): Innovation fund for developing and/or trialling new approaches: I think as well as service providers some consideration and recognition should be given to people-client initiatives, and we recommend our model as an example of something there. I've been on this more or less full-time for the last 14 years and I think there have been gaps that people didn't know existed, and it's really only been by sort of moving and trying to either work through it or go around it that Chris and others have benefited. We don't want to get stuck in the old ideology, the disability and health ideology. World Health Organisation called for the two to come together in 2001. So we do have to look at something that perhaps won't come necessarily from service providers.

MS SCOTT: Okay, just see if I've got it right, because I want to make sure I understand it. This is the idea: that while we've referred to the innovation fund as helping service providers innovate, what you're suggesting is that where maybe, for example, something not dissimilar to your own group - where there was a support group which said, "Look, there's a gap here in services," the NDIA could say, "Yes, it appears to be a gap in services," that the innovation fund be used to test propositions for improved service offerings in those areas.

MS NOLAN (IP): Mm.

MS SCOTT: All right. Well, I don't think I'll lose any great sleep tonight over that small suggestion there. John, do you have any questions about that idea?

MR WALSH: It's a great idea.

MS NOLAN (IP): If I could just say one more thing. We've sought out - one nursing home closed in 2005 and because nothing had happened with COAG at that stage, we agreed that Chris would go to another nursing home as an interim, with a package of funding. I don't know how many nursing homes I went to and I was almost desperate, but it was where people would meet us where we were and take Chris on, not start back where they thought he should or could be, so it's that partnership - - -

MS ATKINS (IP): I think that's where the real importance of that is for people who - like family members who don't have someone who can advocate so strongly for them, which is what we try to do. They just get lost in that system and are back in that system. It's a real tragedy for some and we've experienced people who have died from inappropriate care.

MS SCOTT: Yes, I'm sure that's the case. Now, you asked me a few quiz questions along the way: was I aware there were four levels of this and five levels of that? You know, part of the audience we have, of course, is politicians and government officials and so on who won't actually be expert in this field, just as our team was far from expert when we undertook this task. John is very expert but I'm just a simple economist. Is it possible for you to write up - and I wouldn't go beyond an A4 page, in fact maybe half an A4 page would be better - something whereby you could illustrate how you see a new service offering coming from, say, a family or parental support group and maybe drawing on your own experiences to demonstrate that?

Not everyone will be familiar with your organisation or familiar with your experience and you'd have to write it in a way that, well, some non-expert person is going to understand. So it would be best if there was like no medical terminology in it at all - a very plain English version would help. I'd like to see that because I think you've whetted John's and my appetite for this idea, so I would like to see just how that could translate.

MS ATKINS (IP): Great.

MS SCOTT: I wouldn't want to give you false hope. I'd like to see it first.

MS ATKINS (IP): No, no.

MS SCOTT: All right, John, any further questions, do you think?

MR WALSH: No, that's been great. Thank you, Mary and Megan.

MS NOLAN (IP): Can I just say one more thing? Just that landlord service provider and holder of funds need to be in different hands.

MS SCOTT: Landlord?

MS NOLAN (IP): Landlord service provider and holder of funds. I think that's been very evident. So the aged care for us is the core and we have an organisation and case management holding our funds, but in the block-funded 10-person place here in Victoria, the same organisation is landlord, service provider and holder of all the people's funds.

MS ATKINS (IP): For the rest of their lives.

MS NOLAN (IP): For the rest of their lives because there's no other alternative.

MS SCOTT: No, I see. So let's see if I understand this. The danger is - and you can, I suppose, have this with supported accommodation as well.

MS NOLAN (IP): Yes, definitely.

MS SCOTT: "You don't like this, so pack up your bags and walk. Oh, there's no alternative? Oh well, I think maybe you don't want to complain again."

MS NOLAN (IP): Exactly.

MS SCOTT: Have I got that right?

MS ATKINS (IP): Yes.

MS NOLAN (IP): Exactly, and the people become victims.

MS ATKINS (IP): And there was some mention of that in the draft report regarding disability service providers, so we'd like to highlight the accommodation side of that as well.

MS SCOTT: All right, we'll try and remember that and the 7000 other things. It would be useful if you could just raise that in your - - -

MS ATKINS (IP): And would that be in our written response to the draft report?

MS SCOTT: Yes. Look, don't feel you need to write books.

MS ATKINS (IP): No, we'll do a - - -

MS SCOTT: If you could just include those extra things we agreed to along the way, the citing references to things. You've seen our little box that explains thing?

MS ATKINS (IP): Yes.

MS SCOTT: That's where I particularly think that might lend itself to looking at this innovation from - really, innovation almost from support people of users than innovation from the service providers themselves.

MS ATKINS (IP): Yes. That's great.

MS SCOTT: All right. Thank you very much for your time.

MS ATKINS (IP): And one last thank you to everybody.

MS NOLAN (IP): Yes, thank you.

MS SCOTT: We'll pass on your thanks to the team. We really appreciate it.

MS ATKINS (IP): Thank you.

(Luncheon adjournment)

MS SCOTT: Good afternoon, and thank you very much for coming along today and travelling from the Latrobe Valley to be here. We very much appreciate your attendance. So would you like to make an opening statement. We've allowed 30 minutes for your presentation and for us to ask you questions, so just see how you go.

MS TOPS (GCA): Thank you very much.

MS SCOTT: Thank you.

MS TOPS (GCA): My name is Jean Tops and I am the president of the Gippsland Carers Association, and with me is Pamela Trew, our secretary.

MS SCOTT: Welcome.

MS TOPS (GCA): We are very pleased to have the opportunity to speak to the commissioners today about the National Disability Insurance Scheme. We're very pleased to be able to put the issues of unpaid family carers onto the agenda in the debate, because we feel that unpaid family carers are basically maligned, sidelined and ignored, largely, by a system that benefits hugely from our contributions.

What we'd like to say, essentially, is that the Gippsland Carers Association is an organisation that is entirely voluntary, that we are all made up of family carers and/or people who have been carers, and we represent families all across Gippsland. There are about 26,000 families across our region and we've been in operation now since 1997 as a completely voluntary unfunded organisation. So that kind of speaks to the passion that we have to try to make a difference to families who are providing unpaid care at home.

MS SCOTT: Thank you very much.

MS TOPS (GCA): We would like to basically say that we substantially agree with the Productivity Commission's recommendations. Particularly, we are thankful that you recognise that the current disability support system is broken and beyond repair, and we are particularly pleased that you are recommending that there be a completely new system, that is funded by the federal government as core business, to take care of people with disabilities and the families who take care of them. It should be the responsibility of our national government, and it's something that we have supported and lobbied for for a very long time, decades in fact, over many inquiries and many submissions and many processes along the way.

People with disabilities should not be second-class citizens. They should be treated by our federal government as equal to people who are over 65 in terms of the support that our federal government gives to them. We would just like to raise some particular issues that pertain to the family carers themselves, to high-level urgent waiting lists that are out there at the moment, and to talk as far down our list of concerns as we can in the time that we're allowed, in terms of the issues about carer payments and their involvement in or out of an NDS, transport issues for people with disabilities, mainstream education and whether that should be in or out, the assessment processes, particularly as they pertain to family involvement, and the issues of the Quality Framework for Disability Services that might be in play as a result of a national disability insurance scheme coming to be.

MS SCOTT: Yes.

MS TOPS (GCA): We will put our issues of first-order concern before you first; that is the issue of the current high levels of urgent unmet need for accommodation and support services for people with disabilities. We know from customised data that we obtained from the SDAC in 1993 that there are 55,600 people who are now over 38 years old who are living with parents carers who provide them with an accommodation and support service. All of those family carers are aged, elderly, frail, stressed, ill and worried about what's going to happen to their person when they die.

We understand that the commission are recommending that there should be up-front funding made available to deal with unmet urgent need, but we are concerned about what happens to all of those families and all of those people with disabilities in the interim if we're waiting until, at the earliest, 2014, and at the latest perhaps 2018, 2020, for a new system to roll out. That's going to be ever so much too late for the families who are at the moment at breaking point and for the people with disabilities who are themselves middle-aged and heading toward old age, who are in crisis care situations today.

So to demonstrate that a little further down, in Victoria there are more than 3000 people on accommodation and supported accommodation waiting lists. Those people are waiting a minimum of decades for a supported accommodation service. So when they fall into crisis - the family member dies, becomes too ill to care - they're shoved into every manner of crisis accommodation - respite beds, supported residential services that are grossly inappropriate for them, hotel rooms, motel rooms, community flats and units - without the support that these people need, and they are getting into so much difficulty and they are under so much duress and they are suffering exploitation, abuse and neglect.

We would like the commission to be far more assertive and far more powerful in your recommendations that those issues of crisis that are happening now ought to be addressed up-front before anything else happens with a national disability insurance scheme. The federal government currently only provides about one-fifth of the funding for disability services across Australia. That is appalling and the federal government should be ashamed of itself, and it should stand up now and provide an injection of funding into the current system to prevent those terrible situations from continuing.

In terms of supporting unpaid family carers, we recognise that the commission understands and expects that unpaid family caring will go on into the future, but your deliberations don't seem to take into account, really, the level of support that unpaid family carers currently don't have and which they should have and what those supports ought to be. We recognise that you are suggesting that family members who are primary carers should be eligible for an assessment, along with the person being assessed, but nothing seems to happen past that. So the assessment process, as we can see it in your paper at the moment, suggests that people might be able to be referred for counselling and/or training or some such thing, but we want you to accept and appreciate that unpaid family carers need much more than that.

MS SCOTT: What would you suggest? What would you add to that list?

MS TOPS (GCA): The very first thing is the establishment of regional carer support networks throughout the nation. Gippsland Carers have been running essentially an unpaid carers support service in Gippsland since 1997. People who are housebound, caring for children and young adults and older adults with a severe or profound dependent disability, are essentially prisoners in their own homes. They need support on the ground, grassroots, where they can access it by picking up a phone and saying, "Can you send someone to talk to me because I have this urgent need for a support service, I have this urgent need for making an application for a carer's allowance and I don't know how to do it. I'm terribly stressed. I don't know what to do with Johnny. I desperately need you to help." So we need those services to be funded under a national disability insurance scheme to ensure that family carers actually get the on-the-ground peer support, personal support, grassroots access, that they have a right to expect.

We have on a number of occasions raised that issue with both state and federal governments. We've even gone to the extent of making submissions through the National Carers Coalition to the federal government budget process, asking that funding be made available on a national basis for those services to be established. At this point in time, we're being whitewashed by the system, who don't think that, as unpaid family carers, we really deserve to have that. So what we want you to understand is that we do deserve to have that, that our contributions are worth $30 billion to $40 billion a year to the national economy.

Carers are getting so stressed that they are opting out of caring. Unless we do something really big to shore up those arrangements with families, to encourage them to continue caring with the support they need, there's not going to be a 7 per cent annual reduction in unpaid care. It's going to be much, much bigger than that. In particular our younger parents, who see what is happening to their older peers around their locality and around their state and around their nation, are putting up their hands and saying, "(a) we both need to be in the paid workforce and (b) we are not going to put up with what our grandmothers and our mothers have put up with. We're just not going to have that. So you are just going to have to provide the alternative services."

MS SCOTT: Jean, can you remind me how much your budget proposal is?

MS TOPS (GCA): Yes. We have costed a proposal to establish 42 regions in Australia, which represent essentially the departmental regions as established by the community services departments across the nation - at 42 to 44 regions - and that each region would take half a million dollars to provide an on-the-ground support service that would include paid careworkers who would be in vehicles going all over the region, meeting with families in their own homes; would do very basic management with an office manager and a half-time clerical support person, nothing more than that; nothing grand, just on-the-ground people who can encourage the establishment of local support groups to get family members out of their own homes and actually acting and reacting with their own local community. Unless there are paid people who are able to coordinate and organise those things, they don't happen. And we would encourage and empower families to take control of all the issues that are affecting them. So we're talking about a $22 million annual budget which, compared to a $30 billion to $40 billion contribution, is like postage stamp money but nobody wants to listen to us, nobody wants to hear what we are saying.

MS SCOTT: Thank you.

MS TOPS (GCA): So then we get down to the unpaid carers who you have discussed in relation to their carer payments and their carer allowances and whether they should be in or out of an NDIS. Quite clearly they should not be, because carers payment is income support and, in anyone's language, a person who's got a carer payment is getting income support and so it therefore does not belong as part of a disability support service. The same thing applies to a carer allowance which is being paid to a carer in recognition of the work they're doing.

Given that the carers allowance is about $116 a fortnight and is a token of a contribution to families who provide full-time unpaid care, it certainly should not be included in calculating how the NDIS should be funded. In fact, we would go even further than that and we would say that there is a very strong argument (a) for the carers allowance to be immediately doubled and (b) that the carer payment that is being paid in recognition of someone's unpaid care service for a person with a dependent disability should in fact be made means-test free, so that your unpaid family carers who are providing full-time accommodation, personal care and a support service 365 days a year are actually being remunerated for the work that they do in a small way.

You're talking about a pension of about what, $16,000 or $17,000 per annum, opposed to a full-time care and accommodation service of anything between $100,000 and $160,000 per annum. It's a very good quid pro quo to say, "Let us resource the families to encourage them to continue caring." The entire society benefits enormously from that happening.

In relation to the transport issues that you are asking people to make a contribution about, and the fact that multipurpose taxi services are so expensive and is there an alternative, we'd like to bring to your attention an issue that is currently happening where we live, and this applies most particularly to rural and regional and remote areas, where multipurpose taxis and in fact maxi taxis are so thin on the ground that we have a family that live 30 kilometres from the centre of Latrobe City. Their son has just graduated to go into an adult day program service, so therefore the bus that was paid by the Education Department to take him to the special developmental school will no longer take him to his adult day placement.

The family tried to get a maxi taxi arranged to take their son to his day program and the maxi taxi service told them that they were so short of available vehicles and drivers that they would not be able to pick him up before 10 am and that they would in fact have to return him home at 1.30 pm because they couldn't fit another person into their schedule. The cost of that maxi taxi for the family was going to be $200 a week. There are other families who live a little further out who are being asked to pay - and in fact do pay - regular taxis to take adults with disabilities to day services and to sheltered employment services where the family are paying $250 a week, and that's with subsidised taxi care.

There has got to be a better way to provide transport services for these people and perhaps a leaf needs to be taken out of the Education Department book, where they find it feasible to pay for private buses to actually be made available to do the rounds and the routes within the regions and the systems, to pick up and take people to their appropriate programs.

A fairly similar thing happens in education services and how they will relate to the NDIS, because the children with disabilities, particularly those with profound disabilities who attend special developmental schools and/or mainstream schools, are in terrible trouble because there are insufficient resources made available for teacher aides and personal care support. So we have a number of stories that we can tell you about how a child with autism has been sent home by the school on an arrangement where, "You have him for two days a week and we'll have him for three because we can't get any more teacher aides than that and we can't manage to take care of him without the teacher aide support." So the family are forced to keep their son home two days a week because the schools maintain that they cannot provide the support he needs to be in an education service, and that's fairly uniform and fairly consistent.

We have, for example, a family at the moment who are suing in the Federal Court because an education system doped up their child so much that he was given three times the dose that was normally prescribed for a child of his age with an autism spectrum disorder because they could not control him, in their view, because they didn't have the necessary supports. So we need you to consider how the NDIS will need to be involved to ensure those children do in fact get the education that they deserve to have.

MS SCOTT: In terms of the child with disabilities who is only able to go to school three days a week out of the five, are the parents or is your organisation taking that further with the Education Department? I'm just interested in how that sits with the obligations of the Education Department.

MS TOPS (GCA): We have encouraged the families to raise the issue with the Education Department, but we have this real issue, don't we? There's this balance of power thing that goes on here. If I push too many buttons down here because I want my son at school for five days a week, the power imbalance will say to me, "Oh well, it's just not possible for us," so if you want to keep doing that, you'll end up having to have them at home five days a week. And there is this emotional blackmail thing that goes on all the time, and there are lots and lots and lots of family carers who are so browbeaten by the system that they are terrified to speak out lest they lose what they already have.

MS SCOTT: Yes, I understand.

MS TOPS (GCA): So we do try to empower carers in those circumstances. We have gone in to bat for people who have those issues with regard to their transport and the fact that the Department of Human Services has also told the family, "Oh well, look, the only way you're going to get your son to go to the adult program will be if you can take him yourself because you've got a modified bus."

This mum has got two children with profound disabilities, both of them wheelchair-bound, both of them, up till this year, able to go to the SDS. Only now one has to go to adult because he's turned 18. So mum is faced with this thing of: "How the heck do I get him to the day program when I've got my other son who is waiting for the bus to go to SDS?"

What has happened, the department has said, "Oh well, you could do that." So mum has said, "Well, will you pay for the extra in-home care service to look after child number 1 while I take child number 2 to his day program?" "Oh well, you're asking for a lot, because we already provide you with this much support and this much support." She said, "Well, will you pay me the $60 a week that I need for petrol to drive my own bus?" "Oh, your son has got a disability pension and a mobility allowance, can't you use that?"

This is what families face on a daily basis because the system is broke, under-resourced. Departmental people put it back on families. That mum is in fact driving her son to his school every day, then racing back to make sure that the other one is okay for his bus, and, on top of that, has to take her normal child to get on the train to go to his secondary college. She is totally beside herself. It's a broken system.

MS SCOTT: Okay.

MS TOPS (GCA): Then we get down to the issues of assessments and the use of what you consider to be the reasonable test in terms of deciding what level of support an individual would get. I guess my question is: who decides what's reasonable, and is there a formula which says, "Reasonable equals this"? We would like you to consider that particular issue a bit further in terms of what you consider is reasonable under a reasonable test and then, in taking into account the role of the family in caring, what equals reasonable for them?

MS SCOTT: Jean, maybe we should have a discussion on that now, if that's all right with you. Are you comfortable with that?

MS TOPS (GCA): Yes, sure.

MS SCOTT: I'm not too sure we can go a whole lot further. I'm happy to take it on board, and John may have a different view, so we might end up having a good old discussion about this, because people's circumstances are just so different. I mean, we've had a number of groups present to us in the last couple of days and whilst they've presented very well, a number have said, "You haven't spent a lot of time on acquired brain injury," or, "You haven't spent a lot of time on autism," or, "You haven't spent a lot of time on the aids and appliances for people with vision impairment." I'm just very conscious that we've already got an 800-page report - - -

MS TOPS (GCA): Yes, I know.

MS SCOTT: - - - and everybody's circumstances are quite unique.

MS TOPS (GCA): Yes.

MS SCOTT: You could find that you'd have two people who have what may, on paper, look like similar circumstances, but until you've actually talked to them and met with them and had some sense of the supports that are around them - their aspirations and their individual needs - how are you going to be able to write a report about 360,000 people where 360,000 people are each going to have different circumstances?

For some people, home modifications would be entirely reasonable and necessary, but we know from the New Zealand experience that some people have said, "Well, we want a lift in our house." A lift was provided, then they moved house, and they needed another lift because they went and bought a three-storey house. Now, for a person in a wheelchair, you might say, "Well, that might not have been the best purchase."

MS TOPS (GCA): Yes.

MS SCOTT: So what's reasonable and what's necessary, I don't think we can, with five years' hindsight, guess what that's going to be for every individual, but we have indicated, over a page and a half, the sort of appliances that we're talking about, the sort of therapies we're talking about, and that we would want to see allied health professionals undertake this task. I'm just an economist. I don't think I'm able to guess everyone's circumstances.

MS TOPS (GCA): Yes, okay.

MS SCOTT: I think that's the limitation we have. I know it doesn't sound very satisfying, but in the Transport Accident Commission - you know, the scheme that operates here in Victoria - they use "reasonable" and "necessary".

MS TOPS (GCA): Right.

MS SCOTT: They do need to have it carefully calibrated, because we don't want to find that something is unfair to one individual: you know, why should somebody in Latrobe Valley get X and someone in north-east Victoria get Y? I just don't know how you'd ever nail this down. It's a bit like saying to a judge, "In every case you must find the sentence should be seven years." In some cases it might need to be longer than seven years. In some cases it might need to be seven years. John, do you want to help me out here? First off, do you agree with me?

MR WALSH: I agree with you, Patricia. I think it's something that's going to evolve as the scheme develops. We do have experience from those schemes, so there is an understanding of how this might be done, but I don't think at this stage we can be definitive about it. I think any input you guys have got would be really appreciated.

MS SCOTT: Thank you. Would you like to power on now?

MS TOPS (GCA): All right. Obviously then, in terms of the assessments and the entitlements to a carer to have an assessment, we applaud you very highly for that.

It's been something that we have fought for for decades, that family and carers ought to be entitled to receive support services, which clearly does not happen at the moment. So we are absolutely about 10,000 per cent in favour of assessments for carers and entitlements to support services for them. We just wanted that to be put on record.

MS SCOTT: Yes, sure.

MS TOPS (GCA): Yes, it's been a very, very big battle along the way. In terms of the quality framework for disability service providers, and the monitoring and evaluation of services under a new NDIS, we would just like to make the point that Disability Services at the moment lacks all of those checks and balances entirely.

We would like to see the NDIS set up a system whereby there is an accreditation process for service providers delivering services to people with disabilities, that that accreditation process will also have a monitoring process, that there will be sanctions placed on service providers who do not comply with national standards, and that there be the power to sanction service providers who do not measure up, within a given time frame, to whatever the issues are that have been raised under accreditation.

MS SCOTT: Jean, just on that - - -

MS TOPS (GCA): Yes, sure.

MS SCOTT: - - - you might find a bit more comfort in recommendation 8.3, which talks about compliance arrangements, graduated rolling out audits, community visits, senior practitioners, independent consumer surveys, complaints surveillance, use of the electronic data, the fact that there will be lots of - so there might be more comfort in there, because some of the things you're suggesting here we had envisaged in the scheme and it may be we're losing a little bit in the messaging, but maybe you want to just have a look at that just to see.

MS TOPS (GCA): Yes. I've had a look at that, but what's really important is that there do - to be penalties.

MS SCOTT: No, there are penalties.

MS TOPS (GCA): Okay.

MS SCOTT: Okay.

MS TOPS (GCA): And that those penalties will be applied by an independent organisation.

MS SCOTT: The idea was to have an office, an independent statutory position, within the organisation to apply sanctions. I see that you want to have an external sanctions body.

MS TOPS (GCA): Yes.

MS SCOTT: I think that's the only variation there. Jean, we started on the basis that maybe we'd have to wrap up before you got to the end.

MS TOPS (GCA): Yes.

MS SCOTT: But I have read all your material and I appreciate you coming here today. John, do you have any questions for Jean now?

MR WALSH: No. That material has been very useful, Jean. Thank you very much.

MS SCOTT: Thank you.

MS TOPS (GCA): And we're very pleased to provide you with a copy of our proposal for a regional carer support network.

MS SCOTT: Very good.

MS TOPS (GCA): And our paper on the accommodation inquiry in Victoria.

MS SCOTT: Thank you.

MS TOPS (GCA): So that you get a better handle on our understanding of what's broken and what needs to be fixed.

MS SCOTT: Thank you very much.

MS TOPS (GCA): Thank you.

MS SCOTT: Thank you for both coming along today.

MS TOPS (GCA): Thank you very much for having us.

MS SCOTT: All right, that's great.

MS TOPS (GCA): Thank you.

MS SCOTT: I now call to the table Able Australia, please. John, we're just working out the arrangements for the interpreters to be able to speak into the mics, but, where possible, for us to also see the people actually making the testimony.

MS ANDERSON (AA) (through interpreter): Before we start, I'd just like to make sure that you understand the process of what's actually happening here. I'm Carla and I'm signing for myself. I'm deaf. My voicing will be coming from Sandi, the interpreter on my left. Next on my right is Phil here. Phil is also deaf and he will be signing for himself and Sandi will be voicing for him, interpreting for him. Over here we have a deafblind person. That's Heather. She has a tactile interpreter with her there. The interpreter will be listening to everything that is being said and translating that into tactile signing for Heather. Because tactile interpreting is very tiring physically, when I actually have finished my presentation I'm going to swap with Sarah to give her a rest, to give her a break, and that's how the process is going to work. Is that clear as a bell?

MS SCOTT: Yes, thank you very much. Okay, John, we're ready to go? John, can you hear us?

MR WALSH: Yes, Patricia. Can you hear me?

MS SCOTT: Yes. Not the first time, but now I can. Good afternoon. Thank you for coming along today. Would you like to make an opening statement to indicate your name and the organisation you're representing, please.

MS ANDERSON (AA) (through interpreter): Thank you. Is it John I'm speaking to, that I've actually got on the screen?

MS SCOTT: Yes, John is on the screen. He's the associate commissioner. I'm Patricia Scott and I'm the presiding commissioner.

MS ANDERSON (AA) (through interpreter): Thank you very much for your time - from Carla - and listening to us. I'm just making sure that you can hear with the interpretation okay. As I said before, I'm Carla Anderson. I'm the manager of the deafblind services at Able Australia and we establish braille services, we have a number of disabled people and resources we provide to deafblind people. So it's my area at the moment providing services: case management that may be, recreational services and therapy, counselling, as well as speech pathology and also support, individualised support and interpreting services. So they're the different services for deafblind people that we provide.

At the moment we've had some research done by Access Economics. They found between 7000 to 9000 deafblind people in Australia, and really those numbers probably aren't exact, they're not specific, because we don't know actually the hidden number. Parents often don't acknowledge that their child is deaf and blind; it's a very hidden disability, so it's a very general number. We've also found, through the research, that people aged over 65 or people who are older - there might be about 281,000 of those in Australia who are over 65 and have become deafblind and will become deafblind as they go along. So the numbers are growing exponentially.

Anyway, with Able Australia we also have partnerships with another organisation, ADBC, the Australian Deaf Blind Council. This is an information service really for people who are deaf and blind all over Australia. Able Australia provide services to Victoria only. The ADBC has also found common issues with deafblind people - and Heather will explain more of her personal perspective of that later, but really there are many impacts of having deafblind disability. One, of course, is communication. As you can see, we need an interpreter here. Without an interpreter, Heather would have no access to what was happening out in the world. So we know that 90 per cent of the information that we actually receive is through our ears and through our eyes; the other 10 per cent, through touch, through smell, through taste.

So really, deafblind people miss out on an enormous amount. Not being able to hear or see, they can't read the newspaper, they can't watch the television. They can't decide that they'd like to go wherever they'd like to on a holiday, even. They need support to do all of these things, in planning their everyday life, and Heather will explain that to you further.

Getting back to the ADBC, their definition of "deafblindness" is a global, world definition. It's that it affects communication, mobility and access; access is one of the most important impacts that it does have. Through Able Australia, we also have done some research about the mental health issues related to deafblind people. We surveyed about 30 deafblind people in 2008 and what we found was that there was a very high percentage of that group who had mental health issues, including depression, anxiety and panic attacks. Also, suicidal thoughts was another thing. Obviously, deafblindness - you know, not knowing where you're going, not knowing what's happening to you - 94 per cent of that group had experienced those types of symptoms, so obviously these are things that we're faced with in our everyday work, and people with deafblindness in their everyday life.

The deafblind group, through our work and through the ADBC, have found the same thing, that there are two different groups in the deafblind community: people who are deaf and blind; but one group, we would call them deafblind but their primary language is Auslan - such as Heather would need an interpreter. This group, their second language is English, so they would use Auslan as their first language. The other group that I'm speaking about would have grown up with some hearing loss perhaps. They'd be able to use their residual hearing to understand English, and so English would be their primary language and source of communication and then they might learn Auslan later as a third or fourth language for communicating with.

So they're the two distinct groups in the deafblind community, and it's really quite unique in Australia also, because we provide staff - we have to have staff who are fluent in Auslan. We're really the only one service in Australia that does provide that, who has fluent signing staff, and we're very proud of that at Able Australia. Other states don't have that funding or don't have that facility in their states to communicate with deafblind people.

So that actually becomes a huge problem for many deafblind people whose first language actually is Auslan. If they want to learn about new technology or braille, for example, they have to of course access it through English, and if deafblind people don't have a good understanding of English, that makes it doubly difficult for them to learn braille. Braille follows the English language, of course, so that's a huge impact on them. So it's very important that we have fluent Auslan interpreters to support these people, to actually give them training, and Heather will talk on that as well. So that's probably the biggest barrier for deafblind people whose first language is Auslan.

We've been very, very fortunate in Victoria to have developed strong partnerships with TAFEs, with RMIT University. We've developed partnerships with interpreters, with support workers trained in Auslan. Other states do not have that, unfortunately. They haven't had that access, and that gives us broad access here in Victoria.

In New South Wales their primary group is really people who speak English as their first language. They are deaf and blind. But here in Victoria, our perhaps biggest numbers of (indistinct) people are people with Usher's syndrome, and Heather will speak about that. Different states have different priority groups and different focuses, so we need to meet the actual needs of our specific groups in our states.

Through Australia, we have 22 people who are deaf and blind - 22 out of 110 - that have services provided to them. So those 22 have regular support, and Heather will speak about what that is. They have access to funding and they might get perhaps three hours a month support, maybe up to 12 hours a week, but it depends on the level of funding for their support. So you could imagine a person with only three hours a month support - that's all they get. They have to do their food shopping, they have to do their banking, they have to see their doctor, they have to visit friends, and all the other days they're sitting there with no support at all, looking at the wall sort of thing. They have no support, so there are huge barriers for their everyday life.

What do you think about the time? I think it's a good time now to talk about a case study and so I might hand that over to Heather. She is the case study. Sarah is just finishing her interpretation. So Phil is going to do the case study and Carla is going to sit in the spot while Sarah interprets for Heather, who's going to give her story now.

MS SUDWEEKS (AA): Thank you very much, and thank you, Carla, for your presentation. Carla has just interrupted and is saying, "Just letting you know that the people that you're all presenting to are sitting just behind you." Hello everybody over there. And the webcam and the camera is just over here, so Heather is just sending a little wave. Great. And got your wave back. Thank you very much for that, John.

MS LAWSON (AA) (through interpreter): Thank you for the opportunity for me to be here to share with you all my experiences as a deafblind person. My name is Heather Lawson and I am deafblind, and I have Usher's syndrome type 1. That means that my vision has slowly deteriorated because of retinitis pigmentosa. The problem started when I was young and my eyesight has deteriorated as I've gotten older. I have great difficulty seeing things. It's very blurry and I have very limited vision. My brother and sister also suffer from Usher's syndrome and are deafblind.

I rely on sign language to communicate with other people. That is a tactile form of sign language, and I need support to do everything with an Auslan interpreter, who has to be highly skilled in communicating with people who are deafblind. Now, they help me all the time, and to be involved in the community.

In my life, like anybody else, I like to go shopping. I like to go to the bank. I like to catch up with people. I like to travel. I like to go to doctor's appointments and other personal appointments. I like to access the Internet for braille email to communicate with my friends. I have different commitments. I have different things that I need to cover. I need to find out about important information, dates. I need to find out about things that are happening in my life. I like to do things. I don't just want people to support me, but I need to have the technology to support me as well, and that's through telecommunications.

The technology that I have at the moment is a braille TTY, a personal computer with a braille adapter, a portable braille machine for travelling, a braille mobile and, for many, many years I didn't have this technology. I only had a braille TTY at that time and that was through the 90s. Through that time the deaf community advocated for a long, long, long time to help deafblind people access greater technology to help their lives. When my vision deteriorated, I was forced to learn to read braille and I had to fight for a very long time to get support to be able to learn braille. I had a braille teacher but the braille teacher couldn't sign, and there were interpreters who didn't know about braille, so it was important to have an interpreter who could communicate well with the person, my braille teacher, to help me gain a better understanding. So therefore it was an extremely slow process to acquire the skill of being able to read braille.

I finally got better and am capable and fluid in reading braille now, but I have a new piece of technology - I'm just going to get the name of the technology - a new navigator, a braille navigator, which is new technology. I wanted to get it and I didn't have the funds to get it, to buy it, and also I needed somebody to teach me, somebody who was skilled with the machine and computer technology to be able to teach me. I've had to fight every step of the way for people to work with me for many, many, many years, to support me to get IFP funding for the simple things that I've required.

Unfortunately, there's not enough funding. There's not enough money available - sorry, just referring to my notes again - not enough funds that I require to get all the support that I needed. Even just to do simple things like going shopping, travel training or even just travelling myself, to go at any time that I wanted, to buy technology, to buy the newest things that are coming out, I don't have the funds to do it, so I had to decide which items were perhaps more important and I've had to fight for each one of them one at a time, and I've had to fight and lobby for my rights with the government to be able to be recognised as - you know, the same as anybody else, to have the access. And I've found this process to be quite unfair over the years.

Some deafblind people have some hours of support with staff and some don't, and I know that many deafblind have none at all or they have very, very limited support, and they have to wait on a waiting list for over seven years to be able to get their hours increased or to get any support at all, which is really quite bad when you think about it, when you think about the high level of need. We are on a pension and therefore we can't afford the costs of these pieces of equipment or even the services to pay support people. We don't have the funds available to us to be able to cover these costs.

I know that in Victoria the state government have been more supportive of deafblind people than in other states, I'm aware of that, and also we have Able Link which are run by Able Australia, who provide a great lot of support for deafblind people to be able to use telecommunication and communication training and also technology training. Through Able Link staff, we've been able to access that, but they really are only funded to work two days a week which is simply not enough.

I do have some questions that I would like to ask, if I may. Will the NDIS help people like me who are diagnosed with Usher's and a degenerative eyesight? Would they like us to learn braille before they lose their sight so they can see the dots before they've lost their sight totally? My second question is, will the NDIS help deafblind people have access and support to people who can communicate with them and learn about the process of using Facebook? Just referring to my notes again. Will NDIS give funding to support deafblind people to access the world: to go shopping, to travel, to go on a holiday, to use public transport, or even just go to the beach for the day? Will deafblind be supported to get what they want basically?

When I say that, I mean not just a few hours a week but when we would like to do it, when we want; when we want to go out on a whim. Will NDIS give money for adaptive aids, equipment and software programs for deafblind people so that we can be incorporated in the community to access new braille technology because the old technology is old and there are greater, more advanced technologies with large text, large print, mobile phones with braille technology to be able to send SMSs or, if there's an emergency, have some way of being able to be alerted or alert somebody? If we wanted to go and do a short course or we wanted to write a documentary or poetry, learn things about each other and friends through email, videoconferencing; there's vibrating alert devices that can be accessed so we can answer the front door or answer the phone if somebody is trying to contact us or if there's a fire. If we're in bed asleep we can be alerted through vibrating technology.

I guess like all deafblind people in Australia, our goal is to have direct access to you like everybody else. I don't want to have to go through Carla or Phil or other people telling me what I am thinking or feeling. It's better if I can access people directly. The only way deafblind people can do that is to have fair access to both human and technological resources, and that allows us to enjoy a good life and to participate in the community and do what we want when we want to, and we hope that the NDIS will help us to do that. Thank you very much.

MS SCOTT: Thank you. Well, John, we've got five or six questions there, I think. Would you like us to answer them now or would you like to give more testimony?

MS LAWSON (AA) (through interpreter): Carla, would you like to add something?

MS ANDERSON (AA) (through interpreter): Yes, I would like to add one more thing before Phil starts. Carla speaking. I'd like to add something, Heather, before - perhaps we can swap, because I'm going to speak before Phil starts. I'd just like to follow up on what Heather was saying. First of all, Heather, I'd like to say thank you very much for sharing your experiences with us. Thank you so much. It's just excellent. You've got such an amazing memory really.

The two things I'd like to follow up that Heather was talking about is the seven-year funding from Department of Human Services. We have at the moment five clients who are deafblind, similar to Heather. They have Usher's syndrome and their sight is getting worse and worse, and they're on a list and they have been endorsed by the Department of Human Services, that recognised that they actually have a lifelong disability and they will need funding for support. At the moment DHS has no funding to give. There is none available. So at the moment we're going through a lot of red tape, trying to find other funding and sources of funding that we can get, but unfortunately we haven't had any luck. It's very frustrating for the deafblind people and that's what leads to these mental health issues - all of these barriers that they're experiencing.

The last three months, unfortunately we've had five deafblind people who we've had to refer to hospital for falls, accidents, mental health breakdowns, and the five of them are either on the waiting list for DSP funding or they had received council funding. So that's day-to-day support. They did have that, but once they were in hospital the funding was cut off. There was no support for them from the hospital, so you could imagine again those poor five people were stuck in hospital, absolutely no support at all.

So fortunately for them, through Able Australia we actually provided some ongoing support at our own expense. So we had to do that, so that depletes our funding and it leads to more mental health issues in people's lives, of course, so hopefully the NDIS with funding can lead to some lifelong support that belongs to deafblind people so it doesn't matter where they're living, whether they're in hospital or at home, or whosever accommodation, they will have a good quality of life.

MS SCOTT: Thank you.

MR HARPER (AA) (through interpreter):   Phil speaking now. Just briefly, I'm conscious of time and I know Able Australia would like to put this issue about funding into the submission and will send you their submission anyway. My involvement in this really was through the research that I did last year. I'm a research person and I did that for Able Australia and this was the first time ever that there had been actual research into the needs of deafblind people and their telecommunication and technology needs. So it’s the first time in Australia that this had happened. We got funding from ACAN and that's a national group of people who have various telecommunication access.

Carla explained before about the difficulties of access the deafblind people in Australia experience, and Victoria has some but often other states find it very, very difficult to have any access. They're in their home, they're in their parents' home, they have no support services and they don't have any appropriate support, but fortunately we had 71 responses from deafblind people around Australia, which was amazing, and the information they told us comparing the impact of devices was amazing. So we're comparing the general community and the access that they enjoy through technology and technological communications usage to be part of the world and what deafblind people have. So we found that 69 per cent of deafblind people - 69 per cent out of the 71 - had a normal phone line at home, a landline, but only 45 per cent of those actually accessed it.

Mobile phones: 80 per cent of people in Australia have a mobile phone, which is the normal population. Only a small number - 25 per cent - of deafblind people actually access mobile phones, and that's with the support of others. For example, Heather Lawson is a unique case here because she actually has an Easy-Link, which is a device that she can use a mobile phone through, and it's an extremely expensive device but, you know, we finally found funding to get that for her and Heather has very recently just received this and she can now check that and she actually was jumping for joy. It's had a huge impact on her life, having this, as you can imagine; before she didn't have that access to a mobile phone.

MS SCOTT: Sorry to interrupt but, Phil, how expensive is that Easy-Link?

MR HARPER (AA) (through interpreter):   I think I'll ask Heather perhaps. Would you know, Heather?

MS LAWSON (AA) (through interpreter): $3000.

MS SCOTT: Thank you.

MR HARPER (AA) (through interpreter):   Okay. Now, the Australian Communications and Media Authority research said 77 per cent of people in their home have computers and, through broadband, access. 43 per cent of deafblind people have computers but access to email is even smaller. Perhaps under 20 per cent have access to email. Access to Facebook or perhaps Twitter or any telecommunications through webcam is just over 10 per cent. So they have computers but they can't use them. 11 per cent of that 71 could use online banking services; online services such as banking, but that's very few, just over 10 per cent.

I think in summary really it shows a huge lack of technological advice and the isolation related to the communication because we enjoy this telecommunications ability to communicate with family and friends, with anyone. Deafblind people find that very difficult and I think, in summary, that really that shows it supports what Heather was saying before. In my report I will have that in a much more complete form.

MS SCOTT: Thank you very much. All right, John, we were asked a few questions there by Heather and I want to go back to them because I think we could answer some now. I think the first question was about: did we see the NDIS providing early intervention so people could learn braille and see the dots before they lost their sight totally? John, I think I'd be confident to say that we would envisage that that would be part of the NDIS functions. We've used the example in the draft report of people with MS being able to have training so they can retain for longer bladder control, something that might degenerate in time with the disease. This is another example that we might use in the report, so thank you for that idea.

Then you had a series of questions about: would NDIS help with access? So, for example, you said access to Facebook or access to use public transport - public transport training, I suppose - access to go shopping, access to travel, and then you talked about even access to go out on a whim. Now, John, do you want to answer that or would you like me to answer that?

MR WALSH: A general comment. I'll have a go, Patricia, but you might also want to comment. I think my high-level comment is the NDIS is about providing support and I think we need to be guided by you as to what that support looks like. There is, as with any disability, balance between what the NDIS will be able to do and what the overall community infrastructure should do. I think that's an area where any advice you've got or any order of magnitude about what it is that would be required I think would be very useful.

MS SCOTT: For my own part, I do see the NDIS having a role in assisting people with community and economic participation, with social participation. We have suggested that it would be what is reasonable and what is necessary, so we have used examples in the report about people currently receiving assistance in some states for community activities, for assistance in shopping, for assistance in participating in the workplace. This would need to be assessed on a case-by-case basis. It's unlikely to ever be what everybody wants, but it would be based on needs and reasonable access.

Then you had a series of questions, Heather, about technology. So there was a series of questions about technology: the capacity to send SMS, the capacity to be able to access things through technology or human interpreters with a view that you should be able to enjoy a good life - I think that's your words - and again that goes back to the same answer: that people should be able to receive assistance that is reasonable and necessary for them to be able to participate in the community. There's obviously again constraints, but it would depend upon individual assessment. I am very encouraged by the fact that so much is happening in the technology area, and I look forward to getting Phil's survey results so we can have a better look at those. John, do you have anything further to add?

MR WALSH: The only other thing I'd like to add, Patricia, is that I understand the tier 3 funding entitlement, which means that that's available to people who have a severe need for support in core activities, which include communication. I think many of your members - those that you've described as deafblind - would have an entitlement under that criteria.

MS ANDERSON (AA) (through interpreter): Look, just a question. Could I ask a question? Is that all right?

MS SCOTT: Yes, please.

MS ANDERSON (AA) (through interpreter): In my experience with ISP, with clients - I don't know if you're familiar with the ISP in Victoria at all?

MS SCOTT: Yes, a little. Yes.

MS ANDERSON (AA) (through interpreter): It's individual support packages.

MS SCOTT: Yes.

MS ANDERSON (AA) (through interpreter): From Carla. There are different levels of funding, and most of our clients are about between $10,000 to $15,000 a year, so they have that, and that involves transport support, one-to-one support, interpreting support, taxis as well. In the past, for example, if there's a client who wants to buy something like that - SMS technology - then they have to decide which is more important for them: one-to-one support or buying the equipment.

So because this isn't included in the ISP funding, three years down the track we don't know what technology is available, so of course it's a problem with the funding that we have. We're limited. We can't add to the funding. We can't add the needs. I was wondering if the NDIS will have the same issues. I have regular one-to-one crises. Like, if something happens, and they need extra funding for some support, then their funding is gone. Is there extra discretionary funding for those sorts of situations?

MS SCOTT: We've been quite encouraged, Carla, by the ISP approach, and have seen studies of other individually based packages that seem to be a better arrangement than operates in many other states. A $3000 technology can be cost-effective. New Zealanders have told us that their experience is that, if we take an insurance style approach, sometimes what looks like an expensive item up-front can produce long-term benefits for the individual, and we are very keen to take that forward-looking approach.

While I can't be categorical about any particular appliance or aid - I don't want to give a blanket commitment now to what we'll say in the final report - I think you should take comfort from the fact that just because something looks expensive up-front, that it can be a cost-effective solution for a scheme as well as for the individual. Do I need to repeat that, Phil?

MR HARPER (AA) (through interpreter): That's fine.

MS SCOTT: John, do you have any questions for Carla or Heather or Phil?

MR WALSH: No, I don't, except that it would be useful to have some information on the sorts of support packages that would be appropriate for members. You mentioned 9000 deafblind people in Australia.

MS ANDERSON (AA) (through interpreter): Yes, between seven to nine.

MR WALSH: A bit more information about those people, if you have any.

MS SCOTT: Just to go further.

MS ANDERSON (AA) (through interpreter): Sorry, what specific information are you looking for, John: who they are; their age; the type of deafblindness they have; their communication needs? What sort of information are you looking for?

MR WALSH: Maybe, yes, their age distribution, how old they are, and what sort of deafblind support needs they have - if any of that information is available.

MS ANDERSON (AA) (through interpreter): I've got lots of it.

MS SCOTT: Data is the hardest thing for us to find, so we'd welcome that, thank you. John, I think we should wrap up now.

MR WALSH: Thanks very much.

MS ANDERSON (AA) (through interpreter): From Carla. I'm really sorry. I don't know if you're the right people to consult about this, but I had one contact with James O'Brien, who is the NDIS lobbyist or advocate, whatever you call him; I've forgotten his title. I'm trying to establish a special forum for deafblind people themselves, so that they have a better understanding of how the NDIS could actually affect them. Also you, Heather, I think, have a committee that's the NDIS advocacy. Is it possible for NDIS to provide a workshop for people like this, so they can have a better understanding of what it is?

MS SCOTT: All right. Carla, let's just take this in stages. The NDIS advocacy group is separate from the Productivity Commission, so I would suggest that you contact them direct. Now that you've asked that question, and given James's name on the transcript, anyone accessing the transcript will be able to know that you're interested in contacting people. John, I think we can wrap up now. Thank you very much to Heather, Carla and Phil, and to your interpreters Sarah and Sandi. Thank you very much.

MS SCOTT: John, we've got a change of schedule just to accommodate people in the time frame that we've got. We've got Geraldine Collins now going to come forward from the Australian Lawyers Alliance, and then we've got Christine Bigby after that. So we're not going to have an afternoon tea break. Is that okay with you?

MR WALSH: Yes, sure.

MS SCOTT: Good afternoon, Geraldine. Thank you very much for coming along this afternoon. Could you please state your name for the record, for the transcript, and then would you like to make an opening statement. We have allowed 30 minutes for your presentation, but do anticipate that John and I will have questions. So you might take that into account in terms of your own presentation, thank you.

MS COLLINS (ALA): Thank you. My name is Geraldine Collins. I'm the Victorian president of an organisation called the Australian Lawyers Alliance. We are a national body of lawyers and other professional parties with an interest in ensuring there's access to justice, ensuring that people are able to access the legal system in a reasonable manner and, hopefully, in as painless a process as it can be.

I don't really intend to go into a great deal of detail about the organisation because I think the commission has received a written submission when the first calls came and we will be providing a further follow-up submission by the deadline, but that's sort of really just to give the background of me. I have provided a written response, which I've only just emailed this morning to Monica. I apologise for that. I've just come back from leave, so I've spent the last few days trying to put it together and preferred to make sure that it was in reasonable shape.

As an organisation, the ALA would firstly say that we 100 per cent wholeheartedly support the concept of a national disability scheme. We think that it's something that is far overdue. We in our professional dealings, on a daily basis, see people who are in dreadful situations and don't receive funding. So the first point - which is a very strong point - is that we would absolutely applaud the introduction of such a scheme. We've had an opportunity of reading through the draft report. Again, a lot of these points are in the paper, so I'll just sort of really go to them and then perhaps discussion can follow.

We have a concern about saying that there should be what I've called a dual system of having an NDIS and the NIIS. Firstly, I think there's the capacity there for duplication of administrative processes, further bureaucracies, potentially making it more confusing for people as to which scheme they should be under, what their entitlements are under each system. So our submission is that the appropriate scheme would be an NDIS scheme and that could incorporate both streams of the two processes.

We strongly see the scheme as being something that should be in place to capture people who currently do not have access to any sort of funding or any sort of provision of services through any of the current state based compensation schemes. Generally, the state based compensation schemes are for workers compensation and transport accidents and each state has varying levels of support for people. So we see the need for this to be for a capturing of the people who are currently what I'd describe as falling through the cracks, who aren't injured in a compensation scenario, or have got what I'd phrase genetic disabilities. The level of funding for them and services is not adequate and we would say this system is something that could be used appropriately to capture those people.

MS SCOTT: Geraldine, can I just get you to pause there.

MS COLLINS (ALA): Yes.

MS SCOTT: I don't want to put words into your mouth, but I wouldn't mind exploring this a little bit more. So you support the scheme to the extent that it fills in the valleys almost. Does that mean that your association is confident that people who go through the common law system get what they require?

MS COLLINS (ALA): I think for the very vast majority, that would be correct.

MS SCOTT: Okay. So what should happen for the people who don't get what they require?

MS COLLINS (ALA): Under an existing common law system - or as existing, the system that's existing?

MS SCOTT: No, just imagine we're moving to a newer, better world.

MS COLLINS (ALA): Yes.

MS SCOTT: If I understood your argument correctly - I'm happy to be corrected - - -

MS COLLINS (ALA): Yes.

MS SCOTT: - - - you're indicating that you support the idea for people who are currently missing out as a result of the fact that they don't have compensatable claims, compensation claims.

MS COLLINS (ALA): Yes.

MS SCOTT: I just want to take that a little bit further. So that's for the people who miss out as a result of not being able to take a common law claim.

MS COLLINS (ALA): Yes.

MS SCOTT: But for those who do take common law claims, is it your view, the Alliance's view, that those that are able to take common law claims actually do get what they require in terms of care and support?

MS COLLINS (ALA): Yes. It's probably a little bit more complex, in terms of that the current systems - and I know that you're aware - of common law claims differ depending upon how the injury has arisen. So for Victorian people who are injured in WorkCover circumstances or transport accident injuries, their lifetime care is provided under the no-fault scheme of the statutory schemes. A person injured in a public liability medical negligence scenario, their lifetime care needs are provided under the common law system.

MS SCOTT: Yes, I know, but what I'm after is: on the elements that relate to the common law system, are the arrangements, in your mind, in the view of the Alliance, sufficient, adequate?

MS COLLINS (ALA): Yes.

MS SCOTT: Okay.

MS COLLINS (ALA): When there's an analysis done for somebody's particular case - and again I think this is where there's a great benefit in that existing scheme - each case is looked at absolutely individually, the needs are particularised in a great deal of detail, there's a lot of work that's put together, in terms of ensuring that the requirements that that person is going to have in the immediate future and going into the long distance future are addressed, because - - -

MS SCOTT: Okay, I understand that.

MS COLLINS (ALA): Yes.

MS SCOTT: Sorry if I'm interrupting, but I'm very conscious of time.

MS COLLINS (ALA): No, sure.

MS SCOTT: But, therefore, that would presuppose that those people that reach settlement - 90 per cent, 95 per cent, 99 per cent - determination in fact is through settlement rather than through - - -

MS COLLINS (ALA): Yes.

MS SCOTT: So what you're suggesting to us is that in the 99.9 per cent of cases that are settled, the settlement provision represents the right outcome. It's reasonable and appropriate.

MS COLLINS (ALA): Yes.

MS SCOTT: It's never a case that it's deficient.

MS COLLINS (ALA): I wouldn't say never.

MS SCOTT: I just wanted to know what proportion of cases are deficient.

MS COLLINS (ALA): I can't give an absolute, precise figure, so take that on board, but most - the higher proportion of cases would be appropriate, yes.

MS SCOTT: Okay. And for the cases that aren't appropriate, you're not suggesting anything else be done?

MS COLLINS (ALA): I think there's potential for - if it was a situation of saying it was an NDIS scheme - and I hope I'm not going to get into too much of a convoluted legal scenario here, because I didn't want to do that. Perhaps if I can use an example. Currently, people who are accessing a common law scheme, and if they are not able to work, will go on Centrelink benefits. Upon the conclusion of their case, on the proviso that they receive compensation for their lost earning capacity, they are required to refund Centrelink. So there's a basic safety net for them during the period of the case. They then repay Centrelink. It is the same thing that occurs with Medicare. So they're able to access - - -

MS SCOTT: Yes, I understand that.

MS COLLINS (ALA): Yes. So if there was a situation that somebody had received their common law settlement and, for whatever reason, 20 years down the track there was a need for further services that weren't contemplated at the time of their settlement, then there potentially could be the capacity within the NDIS scheme to say, "Well, is it appropriate for that person to receive it?" If they weren't compensated for that particular need at the time of the settlement then it's outside what - they're not double dipping. They have received - - -

MS SCOTT: Okay. Thank you. Could you proceed.

MS COLLINS (ALA): We see that there are great benefits in people receiving a lump sum as a one-off for them. My practice area personally is in the Transport Accident Scheme, so I can talk from the experience of seeing people getting a common law claim, having it resolved and yet still having interaction with the one insurer for their ongoing lifetime care, and it is a situation that causes people concern. It causes stresses. Inevitably at some stage their services will be reduced and/or terminated and they then face the difficulty of working out, "Well, am I now going to go through a process of trying to review that, trying to overturn the decision that has been made?"

In the schemes that are what I'll term pure common law, where a person is able to resolve every aspect of their case, it's a once-and-for-all. Their dealings are over. They're able to get on with their lives. They're able to use their funds in the manner that is most appropriate for them. They're not having to justify their need for a particular thing, which is a very common thing that I see in my practice area. They're having to ring and explain to a person who is a claims officer or a manager of a particular area as to why they think this particular service is appropriate for them. So they're continually having to justify; their doctors are continually having to justify as to why this is appropriate. So we see that there are disadvantages with that as an ongoing proposition for people. Effectively, they never get out of having, in the TAC jurisdiction, one insurance company ruling their lives and it's a big issue for people on a practical level for them, and having self-autonomy over what they're able to do.

I can recite numerous examples as to issues of medical and like services that have been refused by the insurers, and people have had to fight for them, for all sorts of different things. One of the things that came to my mind, reading the report, was the suggestion that providing the ongoing lifetime care under the NIIS, the needs can be tailored to, as and when they arise; we can make adjustments for payments and look at the person's life, how it was beforehand, and make suitable payments. From, again, my personal experience of acting for people in this area for 17 or 18 years, that simply does not happen in a practical way on a daily basis. Again, I'm happy to give you specific examples of cases if that's of use, or of scenarios if that's of use, or if it's not of use - - -

MS SCOTT: When you refer to payments there, you're referring to cash payments to the individual to then get services. Is that what you mean?

MS COLLINS (ALA):   No.

MS SCOTT: You did use the word "payments". I just want to check what you were referring to.

MS COLLINS (ALA):   Okay. Again, there are sort of two ways that it can be dealt with. The normal course of events is, if a particular service is required a request is made through to the insurer to fund it and they will make a decision as to whether it will be funded or not. There is the capacity - again which I think is an interesting point. In 2004 the Transport Accident Act was amended to give the TAC the capacity to provide a lump sum to a person. For example, on 1 January, "Here is X amount of money for you and you're able to use that as you see fit, for these particular types of services, so you're not having to come back to us every time you need to go to the physio or every time you need to get your wheelchair fixed," whatever the actual service needs to be. So there is the capacity for doing that. That amendment came in 20 years after the introduction of the Transport Accident Act and it's actually recognised in the legislation as being, "This is an appropriate way for people to have more self-control over where they obtain their care, from whom and what the manner of that care is."

MS SCOTT: Are you recognising in your reading of the report that we're suggesting that second system?

MS COLLINS (ALA):   Yes.

MS SCOTT: Okay. I just want to go back to your years of experience of the inadequacies of the TAC. Could you just explain, maybe just give me one quick example.

MS COLLINS (ALA):   Yes. I'm not being critical of the legislation. It's just simply the system and the legislation and the manifestations of what that means in a practical sense. I've had a client who was injured in a motorbike accident when he was 17. Motorbike riding was his life. He grew up on a farm and had been doing it since knee-high. It was a great part of his life. From his accident when he was 17, he was rendered paraplegic. He is now 30 and decided that he would like to get back onto a motorbike. We investigated; had an appropriate OT assessment as to what sort of motorbike; how could you modify it to make it safe and so on. So we had all sorts of information, details from various parties, about that.

The Transport Accident Act has a provision that if you don't have a vehicle, the TAC can make a reasonable contribution to the purchase price, so we asked for funding of this, and he was refused because the TAC's view was, "A car is more suitable for you." We had psychiatric evidence that said this was something that made him feel less disabled. He could go out with his mates again; he didn't feel like he was in a wheelchair. This was one thing that psychologically was really important for him to be able to do and it was refused on the basis of, "A car's more appropriate for you." So there was a subjective element coming into it. Now, whether motorbikes are safe or not is not the question, but that's an example of it, where the particular service that was requested was completely within the legislation in terms of it could be provided, but there was a refusal to acknowledge that - this particular person's experiences - this was something that was appropriate for him. I have numerous examples of those that I could raise.

MS SCOTT: Thank you for that example. Please proceed.

MS COLLINS (ALA): I know there is discussion that it's not considered that the common law does provide deterrence. We are of the view it does. I think you can point to various litigations over the years that have occurred. Again, examples: there was litigation occurred of playgrounds. Councils have changed the way that public playgrounds are structured, the type of equipment that's there. That has seen a reduction in the number of injuries. We can point to the asbestos litigation with the James Hardie - sort of one extreme to the other. That has caused changes in the practices. So there is a deterrent value and I think that is something that is real and has to be recognised.

We as an organisation would have concerns about the funding, as to the actual level of the funding. Again, my experience tells me that as soon as there's a squeeze on funding and perhaps there's a downturn in the markets, one of the first things that goes is actually the provision of entitlements for people. The reaction of the insurer seems to be, "We need to tighten the belt, so therefore we will diminish services and the provision of services."

MS SCOTT: And you've seen that in the TAC?

MS COLLINS (ALA): Yes, I've seen that.

MS SCOTT: Can you give examples of that?

MS COLLINS (ALA): We've seen examples where there may be the provision of home services and then that's restricted down and it has to be only for a certain period of time. We've seen situations of reductions in the increases - perhaps the opposite, the increase in the level of medical excess that a person has to reach before they're able to access TAC medical expenses.

MS SCOTT: Do you feel that the way the draft report is written seeks to address that?

MS COLLINS (ALA): It's more in terms of that the concern really arose from what appeared to be an estimate of around about slightly over $1 million per claim. Even within the report I know there was reference to the New South Wales lifetime care scheme. The quantum for the figures obtained from the TAC for a paraplegic I think was sort of $870-odd thousand, but for a high-level quadriplegic it's $5.5 million. So even within the range of figures from within the report there's a huge variation. It sort of ascends from $870,000 to $5.5 million.

Obviously the amount of money that's required is going to be different in every single case for each person, depending upon what their needs are. We're not disputing that at all but the concern arises from saying if the level of funding - if it's been put on the basis that potentially it's roughly $1 million per person, okay, there are swings and roundabouts but for people with extremely high-level needs and if it's a baby in a cerebral palsy situation, the level of need is far, far greater than that. So it puts the funding at risk and it's really in that scenario - say if the funding level is inappropriate either from the word go or it's found over time that it's not appropriate, then the risk is that it will be a cutback and it will drag everybody back to a lower level.

MS SCOTT: And you don't think that's happened in common law jurisdictions in the sense that thresholds have been put on and statutory rates have been changed? You don't see any cutbacks reflecting that?

MS COLLINS (ALA): I think thresholds in terms of - I'm not sure. Do you mean thresholds of accessing or do you mean thresholds in terms of the quantum of damages?

MS SCOTT: Well, I was thinking about the tort law reform as a result of - you referred to all the work that lawyers had undertaken to improve playground safety, but I was thinking just a little bit further on from all the work that lawyers undertook in that area. The reaction of governments then was tort law reform. You refer to potential cost controls and paring back in statutory arrangements, but I suppose I can see paring back in areas where lawyers have been particularly active in terms of common law, just drawing the comparison. Do you see the comparison, Geraldine?

MS COLLINS (ALA): I think certainly from the tort law reforms from 2002-03, that was really about a threshold for accessing the entitlement, as opposed to the entitlement itself, so it created a threshold level of injury that you had to satisfy before you could access in. There are statutory restrictions certainly in the Victorian WorkCover and TAC scheme in terms of the discount rate is 6 per cent. That varies. That certainly can have disadvantages for people, particularly if it's a minor.

MS SCOTT: Yes, but do you see any connection between that and the payouts that were occurring? It's government response to payouts. You don't see any connection between the two? Governments were drawing connections between them.

MS COLLINS (ALA): Yes.

MS SCOTT: You don't personally see that?

MS COLLINS (ALA): No, I don't.

MS SCOTT: Right.

MS COLLINS (ALA): I don't. I mean, the introduction of the discount, what level the discount rate is at and everything, is obviously going to have an impact upon what the quantum is. Areas where you can see that really affecting is with children, but the benefit there is that the money then is invested and they often get very good returns by the time that they've turned 18, if they're able to manage their finances at that stage, if it's not a sort of intellectual disability.

Again, I'm mindful of the time. As I say, the question of funding is simply, I suppose, really a plea of saying it really does need to be enough because the inevitable outcome would be a lowering of services for people, which is something that we wouldn't want to see. We would see the benefit of this sort of system as being it's a provision, as I said before, for people who currently miss out, and we would have some concern about what appears to be sort of a distinction between, well, if somebody has acquired their disability through a particular source, compared to another source.

It seems almost contradictory to say we need a national disability scheme to look after people who currently get nothing or get very poor level of funding, but then we'll create a distinction within that scheme for what I've sort of termed the genetic disability compared to the accident or injury disability, or even the aged care because, again, I think the report certainly recognises that for the elderly they're at great risk of quite debilitating injuries, yet it appears as if the elderly will not be covered under this.

MS SCOTT: Reflecting our terms of reference, I suppose, Geraldine.

MS COLLINS (ALA): Yes, correct. It's a wish list.

MS SCOTT: Right, okay. Thank you.

MS COLLINS (ALA): I do think that it just seems against the philosophy of saying this is something that's appropriate for society but we'll exclude potentially one group of people who may well be in the greatest area of need, or in a high area of need.

Again, briefly, we would have concerns, in terms of once the scheme is implemented, of actually there being appropriately trained staff on the ground. Again this is something I can speak of from my personal experience in my practice area. We see an enormous problem of that. I see an enormous problem and I practise in metropolitan Melbourne. In regional and rural areas it's a very big problem. I've seen cases where there simply aren't appropriately trained carers. We also commonly see problems that there may be the service providers available in the area but they will not do the work for the fee that they've been told that they will be paid.

So it leaves the person who's in need effectively in the same situation as if there was no such access for any benefit at all. That's a really major problem and I suppose we just have a concern that there can be - again, from personal experience, I've had a client who was a high-level ventilator quadriplegic and he had his nursing care cut back to an attendant carer and it was somebody who'd done a few-week TAFE course and it was actually doing nursing duties on this boy, and his life is in the hands of the person who's providing the care to him. Again, that's where it comes down to, well, it's cheaper to put in a 17-year-old who's an attendant carer than it is to put in a highly-skilled and trained spinal care nurse.

So the staffing issue is something that we see as being quite a significant issue that would have to be addressed and that's something I think that really is going to take time and money for the investment in the proper training and having it accessible to people. As I say, in rural and regional areas it is particularly problematic. The final point - if I may just quickly?

MS SCOTT: Yes, please.

MS COLLINS (ALA):   We also would strongly advocate for the fact that people do need an independent right of review. The proposition of sort of having an arm's length internal process we would advocate strongly against. Again, from the sort of period of time - speaking about the TAC, and again I'm not being critical of the organisation as such, they have had an internal review process in place since they were established in 1987. I don't think I've ever seen the internal review process overturn a decision that has been made, and I think the power imbalance that exists inevitably between any sort of organisation and the person is such that they have to have independent representation and I think the review process has to not only be separate but it needs to be seen to be separate so that people have faith in the way that the system operates.

MS SCOTT: Thank you for your presentation. John, any questions you'd like to ask Geraldine? I'm just very conscious of time.

MR WALSH: No, Geraldine. Thanks, that's all very clear.

MS COLLINS (ALA):   All right, thank you very much.

MS SCOTT: Thank you for attending.

MS SCOTT: Now we've got Christine Bigby, if you'd like to come forward, thank you. Would you like to identify yourself for the transcript, and over to you. We've allotted you 20 minutes, so we'll keep you to that, and if you could allow some time for questions we'd appreciate that.

PROF BIGBY: My name is Christine Bigby. I'm professor in the School of Social Work and Social Policy at La Trobe University. I guess I'm speaking particularly about issues related to people with intellectual disability, which is where I've done a considerable amount of research over the last 15 years. There are two sets of issues I want to talk about today. One is in relation to choice and accommodation and the other one is in relation to the ageing disability interface.

First of all, I want to start by saying that I wholeheartedly support this proposal and I think it goes a long way to addressing some of the issues within the sector. It will address the unmet need, but I'm not sure it will address some of the quality issues in the delivery of services to people with intellectual disabilities. I think like anything there will be significant detail that needs to be worked out but there's a lot of devil in that detail and I think we need to set some much clearer principles around the way this will operate.

I guess what I want to talk about particularly is the issue of consumer choice. At the moment, my reading of it is - and in discussion with some of the officers - that there is no restriction - and I'm talking particularly around accommodation choices - on the type of accommodation support that somebody as a consumer will be able to choose in this system. That means that they would be able to choose to live in some of the new cluster developments that have been developing in New South Wales, some of the refurbished institutions that are happening in South Australia and some of the existing institutions that exist in Victoria; we only one and a bit left.

But what we've seen over the last few years, particularly in New South Wales, is the development of large clusters of housing for people with intellectual disabilities. There's a development, for example, called Norton Road, that has 10 five-bedroom group homes on the same site as the old institution. They're clustered together.

MS SCOTT: Sorry. That was 10 five - - -

PROF BIGBY: 10 group homes.

MS SCOTT: 10 five-person homes?

PROF BIGBY: All on the same site.

MS SCOTT: Right.

PROF BIGBY: There's a myth that there are some people who can't live in the community. That's a myth. There's no evidence to support that. There's a significant amount of research that suggests that living in clusters which segregate and congregate people are counter to the aim of this initiative which is around social inclusion and participation. In the report, there are some really clear guidelines that say, "We will only fund interventions, clinical interventions, where there's good evidence and we'll only fund the number of episodes where there's an evidence base."

I guess what I want to do is to draw your attention to the evidence base that exists around quality-of-life outcomes, inclusion and participation for people with intellectual disabilities. There is a significant body of work that suggests that clustering, congregating people together, acts as an obstacle to social inclusion and participation and quality of life.

MS SCOTT: When does that kick in?

PROF BIGBY: What do you mean?

MS SCOTT: Is it the five persons in a home that's the problem, professor, or is it the 10 lots of five persons, and could you point to the clinical material you've got on that?

PROF BIGBY: It's not clinical. This is accommodation.

MS SCOTT: No. I'm sorry, I used the wrong word. I'm interested in the evidential base about the detriment elements that arise out of the clustering and at what point - I'm an economist - - -

PROF BIGBY: Yes, I understand.

MS SCOTT: - - - a simple-minded economist. We're used to curves and at some point something being diminishing benefit. Could you tell me whether it's the five-person bit or the 10 home bit?

PROF BIGBY: There is a huge body of evidence internationally which shows really clearly that the outcomes for people with intellectual disability who live in five-bedroom group homes or other more individualised types of accommodation are far in advance of the type of quality of people who live in congregated care settings.

MS SCOTT: Okay. So 40 is less beneficial than five?

PROF BIGBY: Yes.

MS SCOTT: Okay.

PROF BIGBY: It cuts in. The evidence is really clear that, after a certain size, it doesn't matter how many more. It's still a bad outcome. It's about the difference between small and large, which is the difference between congregation and segregation.

MS SCOTT: Yes, got it.

PROF BIGBY: There is a lot of variable evidence, but there's really hard evidence that says the best institution, the best cluster, will never get anywhere near the best five-bedroom group home.

MS SCOTT: Okay. So you don't have concerns about the five. It's the fact that there are going to be 10 of them - - -

PROF BIGBY: All in the same place.

MS SCOTT: That's what I mean. I've visited some cluster facilities for people with acquired brain injury and there were three lots of four-person - - -

PROF BIGBY: I don't know the evidence - there is very little evidence about people with acquired brain injury.

MS SCOTT: Right.

PROF BIGBY: But the point is that there is a huge body of evidence about people with intellectual disabilities and it's the congregation and the clustering that's the issue, and we've seen over the last 10 years, going back from deinstitutionalisation, so we're getting bigger and bigger accommodation services and that has been happening in the name of choice. It's suggested that consumers want to choose to live in these large clusters. There's a whole issue that needs to be addressed and I don't think is addressed. It's about who is exercising that choice, but that's a separate issue about supported decision-making.

My point is that we need some very clear principles, that choice is one of the principles that informs what happens, but it's also about independence and participation, and that there are some choices that will actually undermine and are contrary to supporting independence and participation, and that if you don't prescribe the accommodation in accordance with the evidence based, then you're going against the way in which you've talked about evidence based interventions in the rest of the report. I can provide you with the references that give that information very clearly.

MS SCOTT: Okay. Thank you.

PROF BIGBY: That brings us on to the issue about quality. Removing the unmet need will address part of the quality in the disability accommodation service system, but it won't address the other part, and I don't think the report anywhere really considers the quality of the delivery of services. It seems to rely on the consumer power and the market.

MS SCOTT: You didn't find recommendation 8.4 relevant? Do you want me to find it?

PROF BIGBY: I don't know what that is but - - -

MS SCOTT: Let me do that, because we don't want to find that we're talking at cross-purposes. Actually 8.3. Just have a bit of a read there. It's a whole chapter.

PROF BIGBY: Yes, I know. You've addressed quality, to an extent.

MS SCOTT: All right.

PROF BIGBY: There's a lot of reliance on consumers being able to choose and to take their choice elsewhere, and we need some benchmarking and we need monitoring around that, particularly for people with intellectual disability who are very poor consumers. The issue then comes back to the support that people with intellectual disabilities need. They will have a bed, they will have a place to be, but the type of support that they need is significantly more complex than the way in which this report is couched, which talks about having carers who will be empathic and will listen and actually don't need any other skills. There's a thread through the report which is a thread about attendant care and, for people with intellectual disabilities, it's much more complicated than that. They need much more facilitative type of support and that's something that needs to be recognised. A lot of those people will never be able to do self-directed care and so you need much closer monitoring and much closer standards.

MS SCOTT: Just to be clear here - sorry, John, if I'm taking the floor too much. I just want to be careful that I understand. In relation to people with intellectual disability, would it be your suggestion to us or recommendation to us that we would suggest that people have to have minimum cert III? Is that your view? What's the minimum training that you want them to have?

PROF BIGBY: It's not about an individual carer's, worker's, training. It's about the ability of the organisation who's delivering a service to supervise and to direct. You can't afford to have - for example, let me read you this. This is a quote from one of my PhD students' interview with a house supervisor. The house supervisor is talking about a person who's a resident in there and she says - this is the house supervisor talking about the resident:

> She could go by herself if she was shown how to do it, but to date no-one has done this. Probably it is because they don't organise it for themselves. They don't pick up the phone or anything, and if the staff don't do it, it doesn't happen.

Then she says:

> And so that means it doesn't happen.

It's not about having individual carers. It's about having an organisation that can support and direct the carers and the supervisors and continually monitor that they're providing facility support that is the maximum inclusion to people. So you're always going to have some form of supported accommodation for people with intellectual disabilities and you need to have organisations that are quality-monitored for the outcomes for the individual. By just prescribing carer qualifications, you won't be able to do it, because the level of support that some people need is so complicated at times.

MS SCOTT: Can I draw your attention to 8.3. Could you just have a look there and see what we need to add to meet your suggestions there.

PROF BIGBY: It's not necessarily about providing consumers with the information.

MS SCOTT: No. Well, this goes beyond information, professor. Just take the time, because we've got there about "monitor compliance with standards, regulations, graduated and rolling audits of providers, community visitors, senior practitioners, independent consumer surveys, complaints". I'm sure it could be added to. I just want to know what I should add to it.

PROF BIGBY: Okay.

MS SCOTT: I'm looking for the words that would help me change the recommendation to what you think the appropriate - - -

PROF BIGBY: So I guess the words are that the outcomes for people with intellectual disabilities that you will measure will be different from the outcomes that you might be looking for for somebody with no cognitive incapacity who is able to direct their own services. So the outcome measures and standards need to be related to the particular group of impairment issues and the severity of the person's disability.

MS SCOTT: Yes.

PROF BIGBY: So just measuring how many times somebody goes out the front door and saying, "That's community inclusion," which is what those sorts of measures do, won't give you any indicator of whether that person with an intellectual disability has a relationship with anybody in the community and is participating. So I guess what I'm saying is that you actually need some finer-grained measures in relation to this group of people, who aren't able to articulate when things are going wrong, and we know that through the sort of abuse that's happening within the system at the moment.

MS SCOTT: Okay. Thank you.

PROF BIGBY: The other set of things I want to talk about are around the ageing interface. You're aware of the unique patterns and needs associated with ageing and people with a lifelong disability, and I think the proposal in the report about people having the choice to remain with the disability system is a really good proposal and I fully endorse that. I don't think it's clear enough at the moment in terms of the mechanism behind it. I think there needs to be a really clear principle that people - and I only talk about people with intellectual disabilities - have the right to age in place if they're in an appropriate place, so if you're in respite care or an institution then I think that needs to be mediated. So I think that principle needs to be articulated and it's really clear that people will need additional resources in order to do that, and my understanding of what you're saying is that people will be able to be reassessed and those additional resources will be able to be provided.

I think there's a remaining issue then about access to mainstream services. People need access to mainstream health services. It's not just that either you're in the aged care system or you're in the disability system. For example, a group home will need to adapt and will need additional resources, but the person themselves will need to be able to access the health system that's related to older people, and we need to recognise that some of those people who need to access the health system will be younger older people, so they will be people who don't meet the age-related criteria of some of the geriatric health services and at the moment they don't fit well. So I think the report hasn't addressed how to ensure that those mainstream services are accessible to people who are ageing prematurely.

MS SCOTT: We do refer, professor, at one stage to the example of some people with intellectual disabilities, with some conditions, who have a higher incidence of earlier onset of dementia and that in fact there may be services in the aged care sector that, over time, would better suit their needs, but people would be able to have choice in their individual packages to take services from what's most appropriate. But you'd like to see further development in the final report on that theme?

PROF BIGBY: I think that needs to be teased out some more, because it's not only services within the aged care sector, it's services within the specialist health ageing sector.

MS SCOTT: Okay.

PROF BIGBY: One of the easy ways of solving this is to identify people with lifelong disabilities as a special needs group within the aged care system so that the age criteria for access to those services is lowered, because the theory that you're working on is that people with disabilities should be able to access mainstream services and that that's a significant strand of what this is about. So if they're ageing in place, obviously they might need some additional services, but they need to be able to access those mainstream ones and at the moment they can't do that because of the age barrier. That's the point.

The other thing is that if we've got ageing in place in principle, I think the grounds on which a decision would be made that somebody needed to move to residential aged care need to be much more clearly spelled out. At the moment that isn't really well spelt out and there's a danger that that gets left to professional judgments and I think there needs to be a clear process around that.

I have some concerns about the cost. As I understand it, somebody would be able to stay in a group home, and what you're saying is that, behind the scenes, the aged care sector might pick up the additional cost for that person.

MS SCOTT: Yes.

PROF BIGBY: I think that's the best solution to that, but there's a danger, I think. You'd need to build in something that says that cost alone wouldn't be the driver to have to move, because - and these are figures from the Senate aged care report in 2005 - the cost per head of somebody in residential aged care is approximately $44,000. The cost per head of somebody in the disability system is approximately $84,000. If you keep somebody ageing in place in the disability system, that cost will go up and up and up, and it may cost the aged care system more than if you just move somebody over. You can see there's a driver there to move people into residential aged care and I think that needs to be acknowledged and dealt with by putting a principle in and some processes around decision-making about moving.

There's an issue for people with lower support needs. There's work that we've done around people ageing in place. People who have low support needs, when they have age-related needs there's a significant degree of change in their needs and it's those people that often end up moving. People who already have high support needs, their degree of change is relatively small and they're usually living in accommodation where mobility issues and hoists and all those sorts of related things are already there, so they're actually in a better position to age in place than people with lower support needs. Again that's an issue about significant increasing cost for those people to enable them to age in place.

Finally, I think there's an issue about the "all or nothing". The way you suggest it is that if somebody needs to move to residential aged care then they become part of the residential aged care system and I think that's important; there will be some people who do need to move, particularly people with mid to late stage dementia. There's no reason why they shouldn't be in the residential aged care system. But at the moment we know that the residential aged care system doesn't have the capacity to provide support for that group in terms of their disability-related needs.

So people in group homes, in particular this cohort who are ageing at the moment, have very low levels of family support, advocates. If they're disconnected completely from the disability system, then they are completely isolated within the residential aged care system and I think there needs to be an acknowledgment that you can continue to get some support from the disability system to address the fact that the aged care system doesn't really understand this group of people and that this is a unique group of people who aren't like other older people. So there needs to be some provision to be both an older person and a person with a disability, even if you're in a residential aged care thing.

Finally, it brings me back to the issue of choice. We know at the moment that residential aged care facilities are really good at providing health care for people with lifelong disabilities: they're not good at providing social inclusion. Again, if you leave it to the market to provide, without some restrictions, there's a danger that you will get some specialists who will begin to fill a market niche, but because this is such a relatively small group of people, in order to have a specialist group - you know, residential aged care for people with disabilities - you're going to have to build something that will draw on maybe the whole state as its catchment area.

I think again we need to avoid the segregation of people with disabilities on the basis of their disability and, in this case, on the basis of their age. So there needs to be some attention to the residential aged care sector. Again, this is about the connection between the two: that the residential aged care sector needs some input from the disability system to ensure that it becomes responsive to this group of people and that we don't just have one or two facilities in the state that are able to provide really good residential aged care for people with intellectual disabilities.

MS SCOTT: Thank you very much. John, do you have some questions?

MR WALSH: Thank you. Thank you, Christine, that was good.

MS SCOTT: Very good. Thank you for your time.

MS SCOTT: Good afternoon, Michael. Would you like to identify yourself by your full name, please, and I think you're representing yourself. Is that correct?

MR MERRETT: That's true.

MS SCOTT: Okay. So, over to you.

MR MERRETT: Okay. I've got some things written down, so I'll just read from that, if that's okay. I'm Michael Merrett. I'm identifying myself as an individual disability advocate and basically I'm here to say that the disability support pension payment rates must double to at least $1300 per fortnight. It's an absolute disgrace that approximately 800,000 Australians live in poverty, especially when the Australian federal government has announced on 24 February 2011 a framework that will implement carbon tax from 1 July 2012 that will dramatically increase the cost of living.

The disability support pension pay rates must double, totalling $27 billion, and must be included in the Australian federal government's May 2011-12 budget. We can demand that the Australian federal government double the pay rates of all eligible disability support pensioners to at least $1300 per fortnight and provide more equitable incentives for disability support pensioners to gain and retain meaningful employment by allowing at least $6500 income to be earned per year before their benefits are affected and provide free access to education. For example, the estimated cost of doubling the disability support pension at the highest pay rate at the full single pension pay rate - that is currently $670.40 per fortnight to $1300 per fortnight - is easily calculated by $1300 per fortnight times 26 fortnights, equals $33,800 per annum times 800,000 people on a disability support pension, equals $27,040,000,000 per annum.

The Australian federal government is not providing any substantial direct financial benefits through income support or increases in the disability support pension to cover the increase in the basic cost of living and it goes against all government rhetoric that claims social inclusion is a priority. There is no financial benefit for the 800,000 disability support pensioners while the Australian federal government spends millions of dollars of taxpayers' money to develop idealistic plans for the future through reports, strategies and agreements like the Way Forward, the National Disability Workforce Strategy, the National Disability Agreement and the National Disability Insurance Scheme.

The Australian federal government plans for the future mean nothing to disability support pensioners in the current financial climate until they implement them, and even then, even if all the great plans are implemented, it will be too little too late. It could take 10 years for all the plans, strategies and agreements to be implemented, while the carbon tax forces the price of living up dramatically from

1 July 2012. Disability pensioners cannot wait 10 years for all the Australian government plans to be implemented while the basic cost of living is set to increase dramatically through the carbon tax.

There are many disincentives to gaining and maintaining meaningful employment for disability pensioners and it's a disgrace that there is such blatant financial inequality and poverty in Australia. People with permanent severe disabilities are treated very unfairly in Australia in many areas of society through decades of successive cruel and incompetent governments. Disability support pensioners more than ever now deserve more financial equality. With 800,000 disability support pensioners and possibly an estimated three million aged 65 years or older living in Australia as of 30 June 2010 who may qualify for the age pension, we have a very large base for negotiation.

Does anyone here by chance know how many age pensioners there are in Australia? I'm having difficulty finding out a number. I've been working on that.

MS SCOTT: Last time I looked it was about 2.6 million.

MR MERRETT: Where did you get that figure from?

MS SCOTT: I think if you contact Centrelink, they might be able to tell you.

MR MERRETT: Yes, I was thinking that might be the case.

MS SCOTT: Or the Department of Families, Housing, Community Services and Indigenous Affairs.

MR MERRETT: Right. That sounds good. That about wraps that up for that part. That's just a new campaign I've just started like yesterday. You probably remember from last time I run a lot of campaigns on Facebook.

MS SCOTT: Yes.

MR MERRETT: They're going very well, too. I'm getting, next year, a couple of tram stops built on Bridge Road that are brand-new prototypes called "easy access" stops.

MS SCOTT: Yes.

MR MERRETT: One in front of the hospital, the Epworth Hospital, and one halfway up the hill.

MS SCOTT: We heard today from earlier testimony, Michael, about how some really good tram stops have been built, but the trouble was the trams still had steps in them, so I hope that - - -

MR MERRETT: That's right. That's a big problem.

MS SCOTT: Yes. I hope the trams will be as good as the new tram stops.

MR MERRETT: Well, this is the thing. Even on Bridge Road, only about one in five trams are low-floor trams, so even if they build this new stock - and I said that to the minister last week. We had an accessibility tram forum at the Sofitel Hotel and I basically yelled out at him, you know, "What is the point doing all this stuff but then we've got trams running through that are not accessible?" no matter how good they are. They say they're just futureproofing. But, you know, it's like all these plans here. They're all plans for the future: "Oh, we're going to do this. We're going to do that," you know. I don't give a rats about what you're going to do. I want to see some action now, because now the cost of living is going up, pensions aren't going up, so.

MS SCOTT: Is there something about our report that you'd like to comment on?

MR MERRETT: There's no income support. It doesn't cover income support or education or - - -

MS SCOTT: It covers income support a little bit, but not a lot.

MR MERRETT: It's a $6 billion strategy or whatever that's going to be implemented.

MS SCOTT: Yes.

MR MERRETT: $6 billion.

MS SCOTT: Well, actually that's a net amount.

MR MERRETT: It doesn't matter. Even if it was four, even if it was seven, I don't care; it's billions of dollars.

MS SCOTT: Yes.

MR MERRETT: And not one cent of that is going to me on the disability support pension.

MS SCOTT: Do you receive any - - -

MR MERRETT: That's not the point. Whatever you're going to say is not the point - - -

MS SCOTT: All right.

MR MERRETT: - - - because the point is that that's a big lot of investment going to set up a big infrastructure of machinery of all people without disabilities. Yes, they might take one here or there to employ. It's all to employ people with disabilities, to manage and regulate the lives of people with disabilities and keep us under the thumb, oppressed, regulated, whatever, and it's all under this cover of, "Oh, we're going to let you choose how to spend your money." The fact is that there's going to be less choices. Already organisations are falling away and sacking people and gearing up for it. So, yes, you might be able to choose where you're going to spend the money, but there's going to be a whole lot less choice and you don't know exactly how good they're going to be, and there's going to be no regulated way to price or check the prices. They can charge whatever they want.

MS SCOTT: Actually, I think you're wrong there. It doesn't say that.

MR MERRETT: I hope I will be wrong, but at the same time it's like, you know, … shutting out all the corner shops. There's no more milk bars on every corner; just Coles and Woolworths control the market or whatever.

MS SCOTT: In the notes you gave us earlier - thanks for doing that - you indicate that you think that $6.2 billion represents the total cost of the scheme. That's not correct. That's the net cost. So the total cost of the scheme is around about $12.5 billion.

MR MERRETT: Oh, right. That's because of the no-fault clause, the other part of it?

MS SCOTT: No, it's because there's about $6.2 billion spent now and we're proposing another $6.2 billion. So it's like two lots of money.

MR MERRETT: Oh, right.

MS SCOTT: Okay?

MR MERRETT: Yes.

MS SCOTT: So that might change your view just a little.

MR MERRETT: Not at all, because the money does not go to the disability support pensioners at all. There's no way of increasing your ability to cover the cost of living when it's all skyrocketing through the roof. It's all to buy equipment or to buy whatever, which should be there anyway. I mean, that's a given. But what about actual disposable income to buy a loaf of bread? There's none of that, and how much are we talking? $12.4 billion, double $6.2 billion, and I don't get one cent of that to cover the cost of living? And they're going to bring in a carbon tax next year? You're joking. $12 billion and I don't get one cent? This is - I'm hiding my rage. Really, I'm disgusted. It's absolutely abominable and disgusting.

MS SCOTT: All right. Is there anything else, Michael?

MR MERRETT: So what can you do? What can you say about that? You look stunned at me. Am I shocking you? Is what I'm saying not correct? I mean, don't I have any merit?

MS SCOTT: All right.

MR MERRETT: And now you've got nothing to say. You cannot say anything, you know. Why? You've got your hands tied behind your back.

MS SCOTT: No, there's a couple of things I could say.

MR MERRETT: You're running a Productivity Commission here, I take it.

MS SCOTT: Mm.

MR MERRETT: Yes, "mm". See? Nothing. And, look, I can't blame you for that. You've got your hands tied behind your back. You know, you're paid for by the government. The whole commission is set up by Kevin Rudd, paid for by the government, so you've got a conflict of interest basically when it comes to helping people like me out.

MS SCOTT: Could you explain that a bit more?

MR MERRETT: You cannot advocate to provide me any disposable income out of the $12.4 billion. You can't speak up for me. All you can go is "mm".

MS SCOTT: Okay.

MR MERRETT: Isn't it true? See? "Okay"? It's not okay. You can't even acknowledge the fact that I'm right.

MS SCOTT: No, actually, I think there's a chance that you've misunderstood the purpose of our work.

MR MERRETT: Oh, there's every chance I've misunderstood, but I know what I'm talking about.

MS SCOTT: Okay. All right, anything else you want to say, Michael, before we wrap up?

MR MERRETT: Well, I'm disappointed that you can't give me any feedback. If I've misunderstood, please explain it to me.

MS SCOTT: Yes, well, I think I've explained about the $12.5 billion.

MR MERRETT: $12.5 billion, is it?

MS SCOTT: Yes.

MR MERRETT: Okay. I'd better get that right.

MS SCOTT: Yes. And I think you might want to have a look at the terms of reference, because they do control what our work can be. This one wasn't an inquiry into cost of living, it was an inquiry into an insurance scheme, so that does - - -

MR MERRETT: Sure, but it does say in the NDIS Productivity Commission report that there's no income support, does it not?

MS SCOTT: No, I don't think so.

MR MERRETT: I did read it. It said no, it doesn't cover income support, in the booklet. I've read that. I've got the booklet. I can find it if you pass it to me. And I've read it on the Internet.

MS SCOTT: Well, I'm happy for you to show me the bit that concerns you.

MR MERRETT: Come on. You know it's the no income support. You run this thing, don't you? Didn't you read through this, and didn't you help write this?

MS SCOTT: I'd like you to refer to - - -

MR MERRETT: Where is your name? Here it is. Surely you're playing with me. You're sitting here running the Productivity Commission, handing me this, and you didn't read this? You didn't help write it?

MS SCOTT: I did help write it.

MR MERRETT: That's your name right at the front. Okay, so you know exactly what I'm talking about. If you could point me to the page, it would help, where it says no income support.

MS SCOTT: Yes, I'm trying to - - -

MR MERRETT: It probably says it multiple times throughout the document. But anyway, you know exactly what I'm talking about. I'll find it once I get a moment, have a cigarette, and then I'll be fine.

MS SCOTT: All right. Well, thank you for coming along today.

MR MERRETT: Well, I'm really glad that I've been able to tell you how I feel, but I'm disappointed but not surprised that you can't give me any feedback. Anyway, I don't know if I've shed any light here or not really, with you. You've given me nothing.

MS SCOTT: Well, it's more an opportunity for us to hear from you. I think we've given you an opportunity to share your views. We thank you for that and we'll now move on.

MR MERRETT: It seems like my views mean nothing to you at all. They're not even really acknowledged.

MS SCOTT: In what sense?

MR MERRETT: In that all you go is "mm" when I say something to you, and then go "okay" and then move on to the next subject.

MS SCOTT: Yes, well, I think that's going to be the way it is because we're now running out of time, so I now have to go to the next speaker.

MR MERRETT: It's got nothing to do with time. You had every opportunity to say something. But I know you can't. Look, I'm pushing you too hard. You've got your limitations, I know.

MS SCOTT: Okay.

MR MERRETT: And that's what's frustrating the hell out of me, you know. Excuse my language. Anyway, I'd better pack up. It's been fun, anyway, but I just don't know what to do with this commission.

MS SCOTT: Okay. Good. Thank you.

MS SCOTT: Good afternoon, Peter. Could you state your name for the record. I understand you are representing yourself.

MR SHERMAN: That is correct, yes.

MS SCOTT: Thank you.

MR SHERMAN: Peter Sherman is my name and I do represent myself. I would like to focus on a particular area which in my view has not been covered in the report, to which I allude with some disappointment. I have made similar submissions before the parallel inquiry into aged care and it appeared that the inquiry found that to be of assistance and I'm hopeful that this inquiry will find it of assistance too; that is, the absence from the draft report and recommendations of any reference to the Australia's obligations in the area of human rights internationally, federally and on the state level.

There has been an inquiry some years ago into the Disability Discrimination Act, which was conducted by this commission, in which there was some reference to Australia's obligations. However, in these two inquiries there has been no reference at all. I need to draw the attention of this inquiry to firstly the obligations of the commission under the Productivity Commission Act to fulfil the obligations in its work with regard to the international commitments of Australia, the country. One of the main purposes of the work done by the commission is to promote public understanding in relation to the industry and the productivity as they relate to the inquiries undertaken by the commission.

In order to be more specific and address the draft report recommendations themselves, I'd like to take you to page 32 of the overview, which essentially encompasses some of the issues that in my submission attract Australia's legal obligations in the area of human rights.

You may well be aware that in a number of states recently there has been a complete review of the laws related to guardianship and administration, which deals with many of the potential consumers of the scheme that has been proposed by the federal government. In my respectful submission it will be remiss for the commission not to take into consideration that there has been, or there will be shortly, a complete replacement of the guardianship law in Queensland. There is a complete replacement of the guardianship laws in Victoria.

One of the main reasons that these laws are being replaced is because the laws are found to be not in compliance with Australia's obligations in the human rights area, particularly at the time when, for example, in the Australian Capital Territory and Victoria there are legislative provisions with respect to the human rights of the citizens of those states, as well as the legislative provisions with respect to the public authorities providing services to those persons in those jurisdictions.

In my respectful submission most of the service providers, as considered by the report, will fall into the category of public authorities, mainly for two reasons. The first reason is that they are likely to be authorities established by an act of parliament; secondly, because there will be organisations receiving funding from the government in order to carry out their tasks. In Victoria, that would classify them as public authorities and subject to the Charter of Human Rights and Responsibilities Act 2006.

MS SCOTT: What if money passes through to the individual and the individual then spends it on services provided by a specialist disability agency? Does that still apply?

MR SHERMAN: Yes, but from a different perspective. Any public authority which is found to be a public authority for the purposes of the charter, in dealing with an individual, has statutory obligations. The final thing is the methods of establishing whether or not an organisation is a public authority for the purposes of the Human Rights Act; in other words, the finding that is accepted by the authorities for its survival is the descriptor to establish whether they are public authorities.

I will continue by saying that even though the terms of reference for this inquiry are about a disability scheme, or disability insurance scheme, it is essentially about people; it is people who are the providers of services and it is about the people who are on the receiving end of the services. In my respectful submission it is perhaps overenthusiastic to suggest, as it is suggested on page 32, that, for example, in the opening sentence under the diagram, under figure 2:

> People with disabilities and service providers would need to be able to complain to, and contest the decisions of, the National Disability Insurance Agency.

In my respectful submission, and based on my experience, that is extremely unlikely. People with a severe disability, people with intellectual disability and other forms of disability will be far from able to do so unless specialist points of advocacy are established in order to represent them in that process. So I would disagree with the assumption that they "would need to be able to complain to". I would say that more work would need to be done by the inquiry to focus on that area. In order to continue that thought, it then continues:

> The agency would have an internal complaints office that would hear complaints about its conduct or disputes about its decisions.

In my respectful submission - and you may have witnessed a number of people over the last couple of days - I would say that it would be most inappropriate for these people to front an inquiry process in person in order to achieve any sort of result in that complaints resolution service. There would need to be specialist services provided to assist those people and to represent them. I also have grave concerns with respect to a proposition in the penultimate sentence on that page that people could appeal to the courts on the National Disability Insurance Agency's decisions, but only on matters of law and not on merit grounds.

That particular statement actually contradicts High Court authority on the topic and you may be aware of a decision in Griffith University v Tang, which specifically said that no statutory or judicial review is available against a statutory corporation unless the conduct complained of is itself in the legislation. For example, if I was a disability services recipient who would write a letter to NDIS and NDIS would not acknowledge my letter, there is absolutely nothing I can do about insisting that my correspondence be acknowledged, even through the courts, because responding to correspondence is not part of the - or I assume it won't be a part of NDIS legislation, so the statutory judicial review will not be available to millions.

There is also considerable doubt that people in receipt of disability supports are likely to be anywhere near capable, both financially and intellectually, to bring Supreme Court challenges against a federal authority, even in situations where their human rights may have been violated. So it's a whole different but extremely close area to what the commission is dealing with because, remember, we're dealing with an insurance scheme where there is likely to be more than one opinion as to what should be done and what the entitlements are likely to be.

If we're not going to consider the human rights and obligations of those who provide the services, the system will not be able to function within the jurisdictional context of the state. It needs to be able to match, or to be flexible enough to function within the jurisdiction of Victoria, for example - to have a specific legislated charter of human rights. There are also international obligations with respect to persons with disability.

I must stress that - and I have seen references to common law with regard to damages and compensation and so forth. In my respectful submission, that is not the number one issue. The number one issue is the compliance with the human rights provisions. Unless we do that we will end up tied up in litigation all the time. It's likely to become unavoidable. I have brought to show you a draft report recently delivered by the Victorian Law Reform Commission. I didn't bring the Queensland draft report, it contains four volumes, but you can take my word for it. The main issue is that the elder law, as it stands today, is outdated in a number of jurisdictions, for example. Disability law is also outdated. There's a constant review of the Mental Health Act and the Disability Act and health acts generally in order to bring them into the compliance.

MS SCOTT: In the few minutes we've got remaining is there a suggestion from you about how we would address the concerns you have that would overcome what you see as the potential pitfalls?

MR SHERMAN: Yes. In prior inquiries, for example with respect to the Disability Discrimination Act, several legal opinions were obtained by the commission from the Australian Solicitor General's Office in order to obtain up-to-date advice on jurisdictional intersections, if you like. I couldn't stress more that it is imperative that the commission receives an up-to-date advice on human rights situations in the Australian Capital Territory, in Victoria and potentially in Tasmania, where they're just about to introduce human rights legislation. In my respectful submission it is those pieces of legislation that would guide what NDIS will be able to do on the ground in the state jurisdictions.

MS SCOTT: While you've pointed to the guardianship case, are you conscious of anything in the ACT which has had a bearing on their disability services in terms of their human rights legislation?

MR SHERMAN: Not as far as the case law is concerned because my main interest is in the Victorian case law, but their statute is very similar to Victorian statute.

MS SCOTT: All right, this gives us an opportunity to raise this with the ACT government when we get to meet them. Thank you very much.

MR SHERMAN: My pleasure.

MS SCOTT: I won't keep this one, but thank you for drawing it to our attention. It's good. For the purposes of the transcript, we'll now adjourn the hearings.

AT 4.37 PM THE INQUIRY WAS ADJOURNED UNTIL
FRIDAY, 8 APRIL 2011