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# TRANSCRIPT
# OF PROCEEDINGS

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**PRODUCTIVITY COMMISSION**

# DRAFT REPORT ON DISABILITY CARE AND SUPPORT

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

**TRANSCRIPT OF PROCEEDINGS**

**AT SYDNEY ON FRIDAY, 15 APRIL 2011, AT 9.02 AM**

**Continued from 14/4/11**

# INDEX

**MS SCOTT:** Good morning and welcome to our public hearings today. Are there any representatives of the media here today? No, all right, thank you. Our hearings are relatively informal but they are recorded for transcript purposes so that other people can see the transcript and follow the hearings on our web site at pc.gov.au. People presenting their material today are not required to give an oath but are expected to be truthful in their remarks.

We will indicate the time that has been assigned but it will be important if you could leave some time for us to ask questions because it's really the exchange the between us that will help us better understand the situation. Written submissions are due with the commission by 30 April. So we would very much appreciate having those by then as we have to complete our report to the government by the end of July. I now welcome the Guide Dogs Association of the New South Wales and the ACT, Dr Graeme White, Sarah Hirst and Jane Bryce, please.

**DR WHITE (GDA):** Thank you, commissioner.

**MS SCOTT:** Welcome. Would you like to make an opening statement. We have assigned 30 minutes to your presentation but understand you're working in with other associations that are also present today so whichever you're like to work it, we understand that you've got 30 minutes.

**DR WHITE (GDA):** Thank you very much. I would like to make an opening statement, if I may, and introduce a number of people. I am in fact the CEO of Guide Dogs NSW/ACT and also the CEO of Guide Dogs Victoria. We have Sarah Hirst here who is a guide dog user and is a public educator for the organisation, Guide Dogs NSW/ACT, and also a client of Guide Dogs NSW/ACT. We have Jane Bryce, who is community education coordinator for Guide Dogs NSW/ACT and we also have another senior manager sitting in the audience as an observer.

We're here today to represent Guide Dogs Australia which is a federated group of guide dog associations that provides services in all states and territories around the country. In that we provide services such as guide dogs, cane training and other services that enable people with vision loss to move safely about the community and gain more independence. A survey conducted by our colleagues in about 2004 of blind and vision-impaired people up and down the east coast of Australia involving in excess of 90 focus groups identified that of the most needed things by vision impaired and blind people orientation mobility or mobility training was regarded to be one of the two most important.

What mobility training actually does is allows people to get about in society, contribute, to get to and from work, to and from home and negotiate the community independently and therefore not be reliant on carers and other. Guide Dogs Australia organisations provide guide dogs and mobility services and a number of other services to around about 12,000 people per year with a focus on our core activity of mobility training and guide dogs.

Last year Access Economics and Vision 2020 performed a review of the economic impact of vision loss in Australia and a small summary was published in - this is for 2009 data - I think June last year and the outcomes and the findings of this particular report were, we think, very enlightening and very important.  Firstly, it demonstrated that the economic cost of vision loss to Australia is estimated to be around about $16.6 billion and in this direct health costs contributes $2.6 billion of the cost.  So vision loss in itself is an enormously costly disability to the Australian population.

If you look at the wellbeing side of things, people with a vision loss have double the risk of falls, have triple the risk of depression, have four to eight times the risk of hip fractures, have admissions to nursing homes on average three years earlier than the general community and are twice as likely to use health services and all of those things are cost strains on society as well as loss of wellbeing and loss of quality of life.  This information is available in the report that we have handed up and we have another two copies if you would like two spares.

**MS SCOTT:**   Yes, that would be good.

**DR WHITE (GDA):**   This information is actually included in this summary and further information can found from Vision 2020 or through Access Economics.  We would not like to take a great deal of time with my opening statement and I would like to focus on three particular considerations and they in turn I guess are pivotal or they focus themselves on the issue of exclusion of certain people that have vision impairment that want to be contributors to society and also standards.  So the first of the three things that I want to dwell on, if I may, is my understanding of the original brief and the document there is a position, I believe, where people over the age of 65 and also people suffering from a degenerative disease will not be eligible to apply for support from the scheme.

**MS SCOTT:**   Graeme, maybe it's worthwhile just clarifying that.  We have suggested in the draft report that people with degenerative conditions of significant severity that would significantly affect their daily functioning would be eligible.  We give an indication of that in a couple of different places in the report and I'm happy to take you to them if that assists you.  In relation to over the age of 65, you quite rightly refer to our brief.  Our terms of reference refers to disabilities not related to ageing.  Discussion suggested that in fact the interest there was in distinguishing a pre-pension population from post-pension population.  So what we've done there is discussed two sorts of proposals in the draft report and obviously sought comment on which of those two, but by all means let me now let you go back to what you were going to say, but I think the degenerative point might be not quite as black and white as you suggested.

**DR WHITE (GDA):** Of particular concern, if I may just make the point anyway, commissioner, are disabilities such as age-related macular degeneration, which is a defined medical condition, but also could be considered as a degenerative disease of sorts. That's a major cause of vision loss in the Australian population, as I'm sure you're aware, and we would be very concerned if things like that were left out of the scheme and congratulate the commission if they're included and implore you to include if it wasn't considered at this stage.

The second thing is in terms of the pension and if pre-pension and post-pension is a consideration, rather than a 65-year cut-off, again there's a very strong not just wellbeing and quality of life argument, but there's a very good and very strong cost based case to suggest that people who wish to work and are able to work and are supported to work up until the retirement age, that they will continue to contribute to society and will continue to have and enjoy a quality of life that is more equivalent to people that are not equally disabled compared to people that may not be supported and have to therefore lean on and therefore drain, I guess, society of the resources we have.

**MR WALSH:** Graeme, would you mind just talking a little bit about the age of onset of macular degeneration.

**DR WHITE (GDA):** I'm probably not best qualified to speak to that. Jane, do you have any thoughts on that or - - -

**MS BRYCE (GDA):** We have a number of colleagues from other organisations that may be more qualified. The risk of vision impairment trebles from the age of 40. So it doesn't mean that when you hit 40, you are going to be vision-impaired. It just means that your risk of vision impairment increases substantially with each decade after the age of 40. Macular degeneration is the leading cause of blindness. So significant or severe and profound vision impairment in Australia, at present, the older you get, the more at risk you are of getting it. Your risk of getting it also increases if you are a smoker, if you have a family history and there is nothing that can be done to prevent it, but there are treatments that can reduce the impact. Somebody from the MD Foundation would be more qualified in addressing that, but that's my understanding of it.

**DR WHITE (GDA):** We can answer that question in our submission, if you like, John. So we implore the commission to include those two categories. That's the first point I guess I wanted to make. As I said, there's a strong cost-benefit case for both of those, as well as the wellbeing case. In terms of going forwards, we also are very aware that there are a million plus people with disabilities at different stages and levels of severity throughout Australia. Obviously the scheme is not going to be able to cover all of those people, so eligibility criteria is going to be critical in terms of the way forwards and we offer to assist in any way that we can in preparing or helping prepare eligibility criteria for the government, and I'm sure our Vision Australia friends will also be keen to assist and help with that, again to allow the commission to fairly isolate and identify those people with a profound and severe disability that require the assistance versus the rest of the population.

The second point I wanted to make was that Guide Dogs Australia welcomes the inclusion of guide dogs into the scheme and we also welcome the appreciation by the commission of the extraordinary value of the guide dog for certain people with vision loss.  This is a wonderful inclusion and will be most welcome by people who qualify for dogs.  However, we also understand here that there is a need for outcome standards.  It's easy for somebody that can see payment from the government to produce a dog at a below par standard, an unsafe dog, and we understand that there is a need to establish standards that state was particular dog might be appropriate and which dog is not.  Guide Dogs Australia is working on developing a standard at the moment.

There are standards for organisations already established by the International Guide Dog Federation and all guide dog schools in the country are qualified and are members of the federation, but we are quite happy to work with the commission to provide this outcome standard and to work on further refining that to the needs of the government.  The second thing is we also have an understanding of the eligibility criteria for a dog.  Not everybody is entitled to a dog or can benefit from a dog and, again, dogs are quite expensive, so we're happy to offer our services to assist the commission in terms of drawing up an eligibility criteria.  In our submission - it will be coming in at the end of April or hopefully before that - we will include samples of both of those for the commission's perusal.

**MS SCOTT:**   Thank you.

**MR WALSH:**   Just on that Graeme, you said right at the start that one of the main considerations of guide dogs is to improve people's mobility, the ability to enjoy the environment and the community and employment.  Is that the basis on which you would determine eligibility, relative support need?

**MS SCOTT:**   No.  The ability of a person to gain benefit from a guide dog doesn't just lean on how much they will benefit and how much they will contribute to society.  It comes down to how mobile they are, how aware of the environment around them they are and a series of other issues, including the ability to look after the dog themselves.

Sarah might be able to speak to that, but when you receive the outcome standard, the standard has been written in a way that can be basically tested by a layperson.  It's not jargonistic, it's short, it strikes at the core of the ability of the person and the dog to work together and it comes back to whether the person is going to gain or whether they're able to use a dog effectively.  So it's a series of different criteria.  Let me move on so we have time to ask questions as well.

The third point that we need to raise:  we note that the provision of mobility services and independent living skills training has not specifically been mentioned in the supports in the table in the commission's draft report, or I didn't see it if it was. We consider this oversight will affect the majority of people with vision loss and will potentially abandon people with similar severity and disability to those who receive guide dogs.  We also note that of the $6.5 billion currently given by the government to various agencies around the country to provide an assortment of disability services, the one key service that is supported currently with blindness agencies is the provision of orientation, mobility and independent living skills training

So if that $6.5 billion is going to be absorbed into the scheme, as was the other 6.5 billion, we may be abandoning people that are currently supported for their orientation and mobility training and this would be quite distressing.  The Guide Dogs Australia organisations implore the commission to include in the scheme support for the provision of orientation and mobility training, the provision of canes and other aids, and Jane has brought some samples here to demonstrate, if we have time, and also training in independent living skills.  The provision of these services will enable people with vision loss to be mobile within the community, more independent, have a greater quality of life and be contributors rather than drains on society, so coming back to the business case again.

In conclusion, Guide Dogs Australia is most concerned about exclusion of people that have disabilities of severity and vision loss that could use support to continue to contribute to society and have a quality of life.  We're concerned that these people be included and we're prepared and very happy to offer any assistance in terms of establishing an eligibility criteria and outcome standards and we implore the commission to include these sorts of disabilities in the scheme as it goes forward. In terms of the orientation mobility services provided, again we're able to and happy to provide outcome standards and eligibility criteria.  We invite questions, if you would like to talk Sarah about her experiences with the dog, before and after or Jane can talk about orientation mobility and various devices and so on.

**MS SCOTT:**   Thank you very much, Graeme, and thanks, Jane and Sarah.  I just want to go back through a couple of things that you wish to discuss and like to get some more context around them.  Firstly, there was never any intention to exclude key skill sets that people would need to have. But try to compress all things down to one page, obviously you end up using broad headings and then people worry that the broad heading doesn't include the skill sets that they may offer.  So we have got phrases in here about community access supports and social independence and full potential. Of course, it would have been better if we used the phrase "living skills training" and "mobility orientation" but now that we've got your advice it's noted, so please don't be worried we weren't attempting to exclude certain things.

I know some people are worried that we didn't include a long list of aids and appliances but you can imagine that would have been another volume in itself, but if you wish to provide us with suggested words that you think would cover the type of services and supports that people with vision impairment require, we would be happy to consider that. So in some ways that is a small omission just simply reflecting the need to condense it down to a page, nothing more than that. I am interested in the 6.5 million that goes to orientation and mobility. Could you explain - - -

**DR WHITE (GDA):** No, it's $6.5 billion that's currently - - -

**MS SCOTT:** I've written down billion but I thought I'll - - -

**DR WHITE (GDA):** This is what I got from your original report. My understanding is there is around 6.5 billion currently spent on disability service support.

**MS SCOTT:** I see, I thought you were referring to what was spent on - - -

**DR WHITE (GDA):** No, I wish.

**MS SCOTT:** I wrote down billion and then I thought, "Well, it has to be million." The 6.5 figure is in our report but that relates to the NDA expenditure. I understood from earlier presentations that we'd received from different guide dog groups around the country that guide dogs receive no direct government funding. Is that correct or is that a misunderstanding?

**DR WHITE (GDA):** No, that's correct. There is no organisation in this country that receives funding of any kind for their dog programs.

**MS SCOTT:** For the dog programs.

**DR WHITE (GDA):** Correct.

**MS SCOTT:** For the living skills training - - -

**DR WHITE (GDA):** Yes, there is support.

**MS SCOTT:** How much support do you currently receive?

**DR WHITE (GDA):** I can't answer that question off the top of my head.

**MS SCOTT:** Fair enough.

**DR WHITE (GDA):** Vision Australia receives a certain amount of support across their range of services. Around the country the Guide Dogs Australia group receives nothing in New South Wales, about a million dollars in Victoria from the Department of Human Services and there is a scattering of maybe another five million for the other associations around the country of which none of it is for dogs.

**MS SCOTT:** Right.

**MR WALSH:** Just on that point, Graeme, could you talk a bit about the overlap of the organisations - just this morning we have Guide Dogs, Vision Australia and Blind Citizens Australia - the extent to which people are members of all three or how does it all work? How does it all hang together?

**DR WHITE (GDA):** You guys will correct me when you get up here, I guess. Let start with Blind Citizens Association which is a user group.

**MR WALSH:** We did have the Macular Degeneration Association as well.

**DR WHITE (GDA):** Macular Degeneration represent those particular users and they have, I suppose, a mission of community to the community the dangers of macular degeneration and try to get people to get their eyes tested and so on. Vision Australia is an all-service agency. It was formed around about - you guys are correct - about seven years ago by the merger between four organisations and has merged with other organisations since. It has a national footprint of providing a wide range of services and I will speak to that later. Guide Dogs Australia is a federated group of six organisations basically situated in each state. We work together, share information, share services, share dogs, however, are separate organisations in terms of having our own separate boards. Our focus for the Guide Dogs Association group of organisations is on mobility and dogs. That's predominantly what we do.

Although there are exceptions to that. In Western Australia there's an all-service agency. In Tasmania it's an all-service agency. In South Australia they also providing hearing sensory support as well.

**MS SCOTT:** I wouldn't mind going to the issue of degenerative conditions because I didn't want to leave you with a misunderstanding of what we say in the report. We have this very difficult challenge about the interface between the aged sector and the disability sector. In many areas, not in all areas, assistance is currently age related and when people hit pension age - and the reason why I'm not using 65 because, as you know, the age pension age is increasing, so I'll keep using pension age - there's a change in services at pension age. I appreciate it's not in all areas but that's one common thing.

We have been asked to look at the feasibility of the scheme, effectively to cost the scheme and to see whether it can be created and what it would cost and how long it would take to create and what options there are. The terms of reference indicate that conditions related to age population, population above pension age are effectively to be excluded. That was what the politicians gave us. We can draw attention to issues around that interface, but effectively that's what we have been asked to do.

Incidents of disability does increase with age for many, many reasons but by the time people are advanced in their years, the increased risk of disability is very high for some groups. If the scheme included all disabilities, all frailties that might occur with ageing, effectively would absorb the entire aged care sector and that would mean that John and I and the team at the Productivity Commission would have come up with a report with a very, very large cost and given the direction from the government about how they wanted us to do it and the fact that there is already an existing inquiry into aged care, we tried to work out the distinction between the two. It is not easy. In some cases there is seamless provision of services, in others there is quite a strong clear disconnect.

So what we suggested in this draft, and we're happy to have to discussion with you now - I'm sorry it's such a long introduction to the question but I'll get there - we said, "Given the remit we've got, we envisage that certain people would be receiving individualised packages before age pension age, be receiving individualised supports and that they could nominate at the age pension age which of the two systems they wished to continue to receive services from. So someone born with a significant congenital birth disability would enter the scheme at a very young age, would continue throughout the scheme, and if for example they experience dementia at 50 or 60 years of age they may actually start to wish to receive services from the aged care sector, dementia units, and they may in fact wish to then move to aged care sector.

Other people maybe who had a sporting injury and received services and entered into the NDIS scheme, because the injury scheme isn't in existence, could receive assistance and then at the Age Pension age determine whether they want to go into the aged care service sector or maintain connections with the disability sector, and have exactly the same assessment process in the disability sector and receive exactly the same services from, if they wish, exactly the same organisations; but, importantly, funding would come from the aged care sector. People would effectively have a guarantee of continuation of services, but the aged sector would provide the funding. The advantage of that is that, as I said, you don't end up combining both sectors into one very large all-embracing scheme.

We acknowledge that there's all sorts of difficult interface issues, and that is what I'd like to hear from you about.  We have suggested two options, but you may have a third option you think we should consider.  If you're interested in something that would apply to people with vision impairment, what assistance could you give us in terms of how that wouldn't apply to other people with other types of impairment?  So could you discuss that, and, by all means, take as much time as it takes.

**DR WHITE (GDA):**   It's a very long question.  This goes to half the philosophy behind setting up the scheme in the first place.  Where do you cut it off and how far can you go?   Obviously the government can't afford to support everyone with a disability in this country and everyone with age-related issues.  So it comes back to where do you draw the line in the sand, and my understanding is that the aged care support has different hurdles and has different testing and is not as supportive in certain ways as the scheme is looking to be, in terms of orientation and mobility, dogs, et cetera.

**MS SCOTT:**   I guess in some ways it is about expectations; the expectations of someone who is at 75 would be different from someone who is at 20.  The focus of our report is, as much as possible, about maximising employment potential.  It's pretty hard to say to an 85-year-old, "The system has been created to maximise your employment potential."  So we do acknowledge that the systems, quite naturally, will have in some cases different expectations.  In some cases they could be the same; for example, assistance for people to stay in their own home, assistance for people to maintain as much mobility as possible.  So it's not necessarily in all cases different, but certainly that one is different.

**DR WHITE (GDA):**   Let's assume there are some differences.

**MS SCOTT:**   Yes, there are, and there will be.

**DR WHITE:**   It then comes back to that grey area.  Some things are obvious, if you're born with a disability that is profound and you travel through life - and I don't think there's much argument as to whether that person qualifies or not, as long as they meet the criteria that they have to.  The issue that we are most concerned about - and it seems to be one that is prevalent amongst people with vision loss - is this grey area of people that have a distinct medical condition, the results of a vision loss, and whether you classify that as a medical condition and therefore a disability, or whether you classify that as degeneration of eyesight which happens naturally over time whatever the cause may be.  That is something that hits us in our particular sector of the industry pretty badly.  I don't know whether there are any other disability sectors or subsets of the industry that are as badly affected.

One of the things that occurs to us is that if the objective of the NDIS is to have people working and contributing to society, that may be either working and contributing to taxes or volunteering actively to assist with other people's disability or other community services. Then if you have somebody that comes down at pension age or just after pension age but is still working till 70 because there's been a global financial crisis and their super has gone to the dogs and they can't afford to retire at that stage, and they're contributing very, very strongly but all of a sudden they develop a medical condition which is known as acute macular degeneration and all of a sudden they say, "Well, for me to be able to continue to contribute I need a dog or I need to do something, I need help from someone," and we're saying, "Sorry, you've passed the cut-off."

That's what concerns me. It's this grey area. I suppose what we implore the commission to think about is some eligibility criteria, a bit more flexible, but take into account people that have a genuine disability and a genuine medical condition who could be wandering around that age of retirement but still are contributing.

**MS SCOTT:** Graeme, you keep mentioning someone working; would you have the change in eligibility or the change in scheme be related to employment status after aged pension age?

**DR WHITE (GDA):** I think you could probably do that, and we'd love to work with you and some of the other players in the room, such as Vision Australia and BCA, work on eligibility criteria. That's critical.

**MS SCOTT:** I think we should take you up on that - - -

**DR WHITE (GDA):** Excellent.

**MS SCOTT:** - - - because page 13 of the overview is the key page in terms of eligibility criteria, and we have in here that someone would be eligible for the scheme that we're working on if they have significant limitations in communications. Communications include obviously communications in writing. Mobility would also be relevant, or self-care. We would expect that people with significant vision loss would meet that criteria and they would effectively be in the scheme, but you're worried about the later onset of people in people over aged pension age.

**DR WHITE (GDA):** Who are still contributing; who we want to continue to contribute, yes.

**MS SCOTT:** Yes. I guess we're now going to be going on to other hearings and we will be doing lots of work. If your submission could suggest word changes - specific word changes - that you would like to see in relation to the eligibility criteria on page 13 that would assist us a great deal because, unfortunately, we've got a very small team working for us and we've got a very significant deadline. We received over 600 submissions in writing last time, so it's probably not the case that we're going to have the resources to sit down and then work with individual groups on individual words. This is why we're very keen for people to consider their principal concerns and then write to us with actual suggestions that we can then consider. That would be most helpful.

**DR WHITE (GDA):** We would like to help in any way possible and we'll certainly get something to you.

**MR WALSH:** Also - Graeme, Sarah and Jane - it would be useful to get the detail of the cost of providing someone with support and, I guess in your case, training a guide dog and the annual demand for those sorts of services.

**DR WHITE (GDA):** Okay. We'll get that to you as well.

**MS SCOTT:** I just want to check my notes for a second. So exclusion from society, I think we're on the same wavelength. It's just a case that we might need to be more specific. I'd be interested in your view about where you might see Guide Dogs position itself in terms of the structure we've suggested; for example, would Guide Dogs want to retain itself exactly in its current role, to see itself as a disability service organisation assisting people to make sure they get the best out of the system. Would you see yourself as a provider of services? People could take individualised packages to you. I'm interested in just how your organisation can see itself in this arrangement. Maybe it's to the side of the arrangement. Have you given that any thought?

**DR WHITE (GDA):** Not a great deal. We try to focus on homing in on the things of the greatest concern to us. We're happy to consider contributing in any way we possibly can. Certainly we are currently service providers but we can help in a coordinating fashion as well, as does Vision Australia, so we're happy to contribute in any way that the commission and the government wish to put to us if that's possible.

**MR WALSH:** Thank you. That's good.

**MS SCOTT:** Thank you very much for coming along today. Sarah, given that we have you here, do you want to say anything about our report. This is your chance.

**MS HIRST (GDA):** Well, the reason I'm here today is more just to speak about my experiences and the services I've received and just to talk more about how my guide dog has helped me with various issues - study, employment and things like that. So if you would like me to elaborate on that I'm more than happy to, but that's entirely up to you.

**MR WALSH:** Yes.

**MS HIRST (GDA):** Sure. I've been severely vision impaired since I was a baby and as I child I didn't use any services from Guide Dogs so I was fairly independent in quite a small community. My first involvement with them was actually to get assistance crossing roads safely. About the same time I started to get teased at school, and being a very proud child I then began to not want any more assistance, and as I became a teenager it became an issue because that independence was really lacking because I wouldn't accept services.

I then approached Guide Dogs to get training with a mini-guide, and I think Jane has got a mini-guide there. It works a bit like a bat, it uses a sonar signal and it will vibrate in the palm of your hand if it detects an object. I had training with that just to help pick up overhanging branches and things like that. I then contacted Guide Dogs again because I'd started high school and started travelling on trains. I accepted cane training from that point, and over the course of several years I learnt the various skills that I required to use a cane safely and independently, and I could elaborate on that if needed.

For me that did take several years, and by the time I started university I was confident using a cane. For me though I applied for a guide dog and was matched up with Allie, who you see down there. The difference that Allie made to me was very much, I suppose, the flexibility of working with a guide dog as opposed to with a cane. With a cane you need a lot of planning to attempt a route of where you're going. With my guide dog I'm happy to travel just with her independently around Sydney, and that's what I do for Guide Dogs, I travel to various locations throughout the week and present on different issues and also interstate. My perspective and contribution is just about what Allie has done for me in terms of my independence and my ability just to move around and to have the confidence to apply for jobs and to work and to study in various locations. I've just moved out of home as well.

**MS SCOTT:** Did you take part in the living skills training or was it effectively you were trained in the use of the cane later in preparing for Allie?

**MS HIRST (GDA):** For me it's very - each program is really tailored to the individual, so for me, because I had a lot of family around my living skills, I just picked up from them so I did not receive services in that particular area. For me it was literally getting the confidence to be independent and to study and find all my lecture theatres, find the library and perhaps the skills to be able to navigate around now, just to be able to work and have the confidence to get out there and do that in a very, I suppose, smooth and dignified way with my guide dog.

**MS SCOTT:** Thank you very much.

**MR WALSH:** Thanks very much.

**MS SCOTT:** Thank you for coming along today.

**DR WHITE (GDA):** Thank you very much.

**MS SCOTT:** Good morning and welcome to our hearing. Would you like, for the purpose of the transcript, to state your name and your organisation and then proceed to give me your opening statement. Notwithstanding that we're just a little behind schedule you, of course, have your full half-hour, so don't worry about that.

**MR MURFETT (VA):** Thank you very for your time. I'm Kevin Murfett, I'm chair of Vision Australia, and with me are my colleagues, Glenda Alexander, who is our general manager of independent living services, and Michael Simpson, who is our general manager, policy and advocacy. I will give an overview, if that's okay, and then pass to Glenda and Michael. We all have just a few but particular points to contribute.

Firstly, we would like to congratulate the commission on the comprehensive disability care and support scheme proposal that you have developed in a very short time. It's great work. We agree that the current system is often fractured and unfunded. Vision Australia, as Graeme has outlined, is Australia's largest blindness and low vision services. I state that for the following reason and that is Vision Australia is a merge of seven previously separate organisations, and the merger was undertaken and has been very successful because we wanted to reduce the fractured nature of our sector and also infrastructure costs, so that we could provide more services to the increasing number of people who are blind or have low vision in our community so that they could enjoy their basic rights to full participation in the community.

Michael and I - and you've heard from Sarah, and there are many other people who are blind or have low vision in this audience that I'm sure you've talked to in the very impressive consultations you undertook to develop this report. We're living examples, I think, of people who are blind or have low vision who can contribute to the community in both a social and in an economic sense given the right supports.

We'll just make a few points and I'll start with my first contribution and that is I would really like more detail - the mechanics aside but detail about how, if there is a transition from block-style funding to individual funding just how that's going to occur and really in two respects and that is to protect the viability of organisations like Vision Australia and also to protect the rights of those people with blindness or low vision who may at least initially fall outside the scope of the scheme. I just think a lot more detail and form of guarantees in that area would be essential for the success of this proposal. So I'll now pass to Glenda who will make her points. Thank you.

**MS ALEXANDER (VA):** Good morning, commissioners. I just want to mention briefly three things: comment on the age eligibility criteria; the need for specialist services, and the kinds of services that we provide, the fact that they're episodic services on the whole.  So Graeme has raised the issue of the age eligibility criteria and we want to reinforce that.  We don't think that disability discriminates on the basis of age.  If you lose your sight at 64, it's the same as losing it at 66 or 67.  The issues are the same.  The skills you need to develop are the same.

We don't think that the caring for older Australians inquiry is addressing disability comprehensively, particularly in relation to the aids and equipment and services for skill development that will mean that people can remain independently accommodated, wherever they choose to be accommodated.  We feel quite strongly about that.  We provide services to 45,000 Australians over a three-year period and the majority of those are over that aged pension age.

We believe very strongly in the need for specialist services.  We're a specialist service provider, as is Guide Dogs.  We don't think that services to people who are blind or have low vision can be provided by generalist services.  We think the maintenance of specialist services is very important and we're interested in hearing from you, if you have a view about how that can be maintained under the proposed funding arrangements.

Then the issue of the nature of our services:  we teach specific skills to people with severe vision loss so that they can live independent lives.  The nature of our services isn't that people are captured by our organisation, they come and go, they come to us, they acquire a range of skills.  They may come back if their vision deteriorates, so it's not a continuous provision of service but it's really essential, so it's important that those people are covered by the scheme and aren't discriminated against because they don't need ongoing support.  In fact we don't want people to need us.  We want people to be independent.  We want to keep people out of nursing homes for as long as possible.  We want people being as productive as much as possible.  Thank you.  I'll hand over to Michael.

**MR SIMPSON (VA):**   Thank you for the opportunity for Vision Australia and other blindness organisations to put to the commission particular elements that we want considered in the final report that will be going to government in July.  I'm wanting to quickly talk more about the issue of eligibility because in the commission's initial report you certainly discussed and covered the issue of World Health Organisation's international classification instrument as a way of underpinning and determining eligibility for the scheme.

The World Health Organisation's own definition of low vision is actually 6 over 18 which essentially means that a person couldn't normally see at six metres what a person with good vision - in quotes "normal vision" - would be able to see at 18 metres.  So we are concerned that given the figures used in the commission's report that this scheme might be open to around 360,000 Australians with severe or profound disability, that the commission hasn't well understood the impact on daily core functions and the limitation of daily core functions for people that have low vision. So we are concerned and would be concerned if a scheme was implemented with a base line eligibility of, say, totally blind or legal blindness as its starting point. We believe that the continuum of vision loss needs to be included and that up to a level of 6:18 which is the World Health Organisation definition of low vision be seen as the eligibility criteria, and particularly given the emphasis in the report around that classification, the World Health Organisation international classification instrument.

The other particular point that we want to pick up on is the issue of early intervention. The commission has certainly honed in on the benefit of early intervention and we are concerned that in the discussion in the paper that people that might be eligible for one element of the scheme - for example, people that are identified as having a daily core function around mobility or communications or self-care - might not be eligible for another element of the scheme, such as early intervention.

We strongly believe that both elements for people who are blind or have low vision are important to consider. So we don't want to see people who are blind or have low vision locked out of one aspect of the scheme, ie, early intervention, simply because they might be eligible for another component of the scheme around the daily core function limitations. As a person who lost sight through a sudden and in my view catastrophic injury at the age of 18, where I was rendered blind as the result of a shooting incident, I certainly benefited from the early intervention and rehabilitation program that Royal Blind Society - which is now part of Vision Australia - provided to me at that age.

Simply being able to access a program of early intervention and rehabilitation services that helped me with mobility, with braille, with living skills, with typing skills, with employment skills and with assistive technology skills, certainly set me up for a positive future. So early intervention is crucial in our view, but then the ongoing impact of blindness and sight loss is that it does affect daily core functions around mobility and communications, particularly. So we want to make sure that both of those elements are picked up in the scheme, and people who are blind and have low vision be eligible for those aspects.

It certainly makes economic sense because the commission itself recognises that early intervention may assist with limiting the impact of additional services down the track, because if a person can be provided with rehabilitation and early intervention services they may then have a minimal requirement for ongoing services, rather than being totally dependent on a scheme.

We believe that greater flexibility needs to be in the scheme so that people who are acquiring vision impairment, and as they go through that continuum of vision loss, are able to access the disability carer support scheme. They're the points that we want to pick up.  Thank you, commissioners.

**MS SCOTT:**   Thank you.  Feel free to call us Patricia and John, Michael.

**MR WALSH:**   Thanks, guys.  I'll just say a few things that may answer some of your questions but, I mean, the purpose of these hearings is for you to give us your views, not for us to answer your questions.  So we'll just put that on the record for a start.  But in saying a few things, I think they will answer some of your questions but they will also give you a bit of homework to do and think about the way in which you consider this scheme.

Let me start with the issue of, if someone gets early intervention they can't get the daily support needs.  I mean, that reflects a way of thinking about the system which we're trying to flip on its head.  The system is not about services, it's about support needs.  So we've got to start thinking about the people rather than the components in the service compartments.  It' not about a bit of a person - the early intervention bit of a person and the daily support needs bit of a person and another bit of a person - it's about the whole person.

I think that answers another one of your questions which is around the way in which block funding might transition to person-centred funding.  That's going to require a lot of work by organisations, such as Vision Australia, and really very many of the NGOs and other service providers, in changing the way you think about your role from one a service provider to one of a support organisation.  So the person comes first, the services come second.

There was something else I wanted to talk about.  It is about this issue of - Glenda, you said you don't believe that non-specialist services can provide the supports that people with vision impairment need.  I suspect that's true at one level, but I suspect it's not true at another level.  I suspect that there's a lot of work that mainstream services can do in making life easier for people with vision impairment. So tier 2 of our eligibility structure you'll see is around referrals, general support, building community capability.  We see a big role for that tier 2 which goes to four million people, so a very much larger representation to people with a disability to - as Graeme said - participate more actively in community life and make a contribution to society.  Patricia?

**MS SCOTT:**   Thanks, John.  I've tried to put a star next to the key points.  I think you were asking us difficult questions, so let's see if I've got them and again if we have to go a little bit over time I think it's probably worthwhile doing.  I'm going to reiterate what John said on the issue of - is someone in the early intervention basket or are they in the mobility basket.  The person could be in both categories of eligibility and we don't want to have small buckets of money where people have to navigate their way around.  We want someone to be able to approach the organisation and say, "I've got early vision loss. I think I need some training. What assistance can you provide me now," and there would be discussion about planning.

Michael, you talked about the assistance you got in terms of living skills and looking forward to employment and, I guess, Sarah's experience in getting around university, and people thinking about the next stage in life and what needs to be planned. So rather than thinking about that eligibility criteria as a series of "ors" or a series of "onlys" in the sense of "only for this service would you get it; not for that one", we're very much about thinking that people would approach the organisation, they would come to the organisation with some questions and views. It's about discussion, it's about assessment and it's about referral.

Now, for some people with relatively insignificant limitations, it may be the case that it's simply a referral to a specialist organisation who wants to continue and that sort of role of very specialist, very organised in providing particular services. In other cases where people are after an individualised funding package - they want home modifications; they want particular therapies; they would like to see particular training; they want assistance with employment aids - then they could be eligible for an individualised funding package.

I guess the challenge I was posing for Graeme and I'm interested in posing it for Vision Australia as well, do you see yourself over time as an organisation that would stand ready to assist people with referrals, a tier 2 type assistance, you know, "We stand ready, we're helping you," or do you see yourself as also wanting to clearly maintain a role in providing very significant supports to people through individualised arrangements? Now, in a case of some arrangements, block funding may be more suitable; in the case of others, individualised funding is more suitable. So we might return to that. I think that means I feel I've addressed the maintenance of specialist services enough.

"Reinforced disability doesn't discriminate on the basis of age." Well, I'm sure that's the case with many forms of disabilities but, as you know, the incidence of disability does actually increase with age. Just as I asked Graeme to think about how they would like to see the eligibility criteria modified, I would welcome Vision Australia's view on that as well, but also though is the challenge that if you write it so broad as to be everybody over the aged care sector, then imagine that you've got a sector that's trying to cater for all the people with disabilities and all the aged care sector and there is thing called diseconomies, something being so large that it becomes unwieldy, and also the issue that it could look so expensive that no government would be prepared to contemplate it. So you might give some consideration to that.

**MR SIMPSON (VA):** Patricia, if I can make a comment, particularly around the issue of the two areas - whether it's the aged care sector or the disability care and support scheme.  For accessing our service, in terms of somebody maintaining some independence and living at home, for a person who, for example, buys a new microwave oven and who wants that microwave oven labelled with braille, then wants the appliance manual put into braille and wants some living skills sessions on how to use their new appliance, then regardless of whether they're 55 or 75 it's, in essence, the same service.  So what we're trying to take some comfort from and find some reassurance around is that regardless of that person's age in terms of them accessing that type of service, we're wanting to make sure that in terms of maintaining independence that service will be available.

**MS SCOTT:**   I understand that.  That makes sense.  We're happy to reconsider the tiers and so on, and reconsider the eligibility criteria - that's why we've got a draft report - and we welcome your suggestions.  I want to go to the issue of total blindness and the continuation of vision loss.  By all means please include your views in the submission, we would welcome that.  But this idea of continuum I guess lies behind our idea of tier 1, tier 2 and tier 3.

In tier 1 we're suggesting that there's a role for the NDIA, the organisation we think the government should establish, to really send strong community messages about ensuring that the community and structures within the community take account of reasonable needs of people with disabilities; so the difference between having something accessible or not accessible, and then the difference between community organisations having an inviting and an accepting approach, versus one of just a charity model.  One of the discussions we were having yesterday is at the moment we've got a large number of community organisations that have to raise money to provide individuals with wheelchairs, and sometimes people have to wait for years so that they can get those.

If we have a system where that is provided in a more timely way but not through a charity model, through effectively based on needs provided by the community through the government, what role is there then for some of those very community based organisations like Rotary and Lions.  Now, it might be that they are about mentoring; it might be that they're about employment opportunities; it might be that they're about community access.  In relation to the issue of total blindness and the continuation of vision loss, tier 1 could be about general messaging; tier 2 about referrals, so referrals possibly to exactly the same organisations that exist now, or maybe it would be to a larger range of organisations or a smaller, but it could be about referral services, assistance there.  When it comes to significant issues with mobility and communications, it's probably going to be about individualised funding packages, but very much that tiered assessment.

**MR WALSH:**   Which I think Michael is totally consistent with, the ICF framework.

**MR SIMPSON (VA):**   We're certainly supporting the principles that you set out in terms of the community being more accommodating, and we have certainly seen communities particularly around our disability - blindness and low vision - moving in that direction, but it's certainly taken an enormous amount of advocacy from organisations, including Blind Citizens Australia, Vision Australia and the Guide Dogs organisations.  So we've seen increasingly things like audible traffic signals, tactile ground surface indicators.  Many lifts and elevators that you get into now will have braille on the buttons and audible announcements.

So the tier 1 element you're talking about, about a more accessible community, is certainly happening.  But still today I can't walk into any appliance provider in Australia and buy an accessible microwave oven, an accessible television, washing machine.  There are still enormous attitudinal and physical barriers that we face.

**MR WALSH:**   That's not going to change overnight.

**MR SIMPSON (VA):**   That's right.

**MR WALSH:**   There's no intention in this report to all of a sudden say, "We're going to withdraw support for those sorts of advocacies."  That's the opposite of what we're trying to do.

**MR SIMPSON (VA):**   Yes.  In terms of tier 2, with the information and referral, we don't have any concern around that other than the sustainability of organisations that might then receive those referrals.  This cuts to the heart of how those organisations - and in our sense, specialist organisations around, for example, braille and assistive technology, such as synthetic speed screen reader technology and screen magnification technologies - are going to fare under a changed regime, particularly if all of the block funding under the NDA currently is absorbed into the scheme and then applied only to that tier 3 level.  That's the concern that we've got.

**MS SCOTT:**   All right.  That's a good clarification and I'm sure we can address that and we should address that more systematically in the report, so that's a good point.  Kevin, I wanted to go back to your concern about guarantees, if that's all right.  One of the things we've heard through the first round of hearings - and we've also heard it through the second round of hearings - is that there are many people who are looking forward to the day when they will get an individualised funding package and be able to exercise choice because they very much feel unempowered in their current arrangements and they might be reliant upon all sorts of services about attendant care and so on.  So they're looking forward to that day and I guess while individual organisations understandably are thinking about long-term viability and funding - and that's an important question - there's also lots of consumers of services who are looking to the day when they will be able to make choice.

I imagine good organisations might have a little tinge of worry but really know that they're well regarded in their community and well regarded by their clients. There's probably a few organisations who treat people with a fair amount of disdain and are very inflexible and don't offer a good range of services but know that they're effectively the supplier of last resort and they will probably find that consumers won't necessarily take the poor services they offer. I guess the question I've got for you, Kevin, is if we ended up suggesting that the government guarantees all services that currently exist, where would we draw the line around really bad providers - and we've heard stories of bad providers; people who are disrespectful to their clients; people who won't turn up on time; people who are unreliable. You'd like to think they would have to change their ways or disappear out of the system. Kevin, how do we respond to your suggestion? I understand where it's coming from but how do you cope with the fact that we wouldn't want to see some of the bad organisations continuing?

**MR MURFETT (VA):** Thanks, Patricia. I totally agree with your perspective, and certainly Vision Australia and other organisations here with us support the human rights principles and congratulate those embodied in this proposal in terms of moving to more empowerment of individuals to make choices and to choose the care and support they require to live their lives as they choose. Absolutely support that. I guess what we were getting at - and you've actually answered part of my concern in talking about tiers 1, 2 and 3 again, because I was under the impression that tiers 1 and 2 were totally unfunded. As has been mentioned all of our organisations spent a lot of our time and resources doing community education, trying to make the general community more inclusive of the needs of people who are blind or have low vision, and we really want to continue that, and that's perfectly consistent with your philosophy and I think the direction you want this proposal to head Australia.

I don't think there's a major conflict except that I was getting more to - I hope to see more details of the mechanics of the transition so that the timing, for example, of moving to an individual package is timed so that the infrastructure for the organisation they will choose has not all of a sudden disappeared because their block funding has gone too early, if you see what I mean. I'm talking as chair of an organisation and I have a responsibility to actually ensure the financial viability. So it's really a mechanical concern that I would just like some more information as time goes on, but I'm very encouraged to hear your further explanations around the tiers 1, 2 and 3. Certainly we are developing a submission and we will relook at our points and make sure we address the issues that have been discussed today. They have been very informative.

**MS SCOTT:** Okay.

**MR WALSH:** Kevin, there is chapter 17 on implementation. While they're broad time lines, the proposal is that the full scheme wouldn't be up and running till 2018, so that gives you a seven-year time horizon. Some people are suggesting that's too fast; other people are suggesting they can't wait that long.  I think the answer to your question is there's a transition that would need to be gone through, and I think a transition should happen, regardless of whether an NDIS happens that is more around individual considerations.  I'd be suggesting that your organisations need to start thinking in that way right now.

**MR MURFETT (VA):**   Yes, thanks, John.

**MS SCOTT:**   Kevin, I don't want you to have false hopes.  It's a very substantial exercise to concentrate on whether we need to - parts of the existing draft report we need to modify and clarify and delete and enlarge.  I mean, the transition exercise for something as big as this would take some time, and I don't think we'll cover it at length because for the people that are currently receiving services, each of their circumstances are quite unique and you'd need to be taking into account, you know, "Are they on an individualised package from Victoria?  What's the arrangements in Queensland and Western Australia?"  They're just so complex, we couldn't possibly get down to providing all the satisfaction that any number of organisations will want, but we will give it some further thought.

I think the mechanics of transition is probably best left to - as we have already indicated in chapter 17 that there would be a full-time task force.  The first thing is, do governments wish to move in this direction - yes or no - or some modified variation of it, and then having established that, establish a full-time task force, work with organisations such as yourselves to then establish the detail of transition.  I think we will be able to say a little bit about that, but probably not enough to satisfy quite reasonably the interests of all the very many diverse organisations operating in the sector.

**MR MURFETT (VA):**   Thank you.

**MS SCOTT:**   I'm taking some comfort that I've put a tick next to each of those key issues.  If I have forgotten something please address it in your submission and we'll be happy to give it consideration.  Thank you for coming along today.

**MR MURFETT (VA):**   Thank you for your time.

**MS SCOTT:**   We're now going to take a break.  I know the Blind Citizens are on next but we're just going to take a 10-minute break please at this stage.

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**MS SCOTT:** Ladies and gentlemen, we're going to resume now, please. I invite Robyn Gaile to come to the table, please. Robyn, welcome to today's hearing.

**MS GAILE (BCA):** Thank you.

**MS SCOTT:** Would you like to identify your organisation, please, and then make your opening statements.

**MS GAILE (BCA):** My name is Robyn Gaile and I'm the executive officer at Blind Citizens Australia. Shall I proceed?

**MS SCOTT:** Please.

**MS GAILE (BCA):** I've prepared a relatively brief statement and you'll find that there are some similarities and parallels with what my colleagues have presented to you earlier today. I thought I'd start by actually explaining a little bit about myself as a person who is blind or vision impaired. I am legally blind and I have an eye condition that is very similar to the macular degeneration that has been referred to by my colleagues earlier. Just to explain what that feels like and what that's like from a functional perspective, the way I describe my vision is that I see a little bit better than blurry blobs. I'll usually then say, "So everyone is beautiful to me, because I don't see zits or wrinkles or age lines or greying hair." That would be very similar to people who experience age-related macular degeneration. I acquired my condition when I was eight years old, so I like to say I was just ahead of my time, having a juvenile form of the condition.

Functionally that means my central vision is affected: I don't have the ability to read print easily; I can't recognise faces; I lack depth perception; however, I have full peripheral vision. When I'm in unfamiliar areas I'll use a long cane to help me to identify the terrain in which I'm walking and hopefully to not fall down some steps. Because I've got the peripheral vision, I can usually orientate myself to a space, but I might not have the detailed enough vision to then locate a specific space within that space. I hope that gives you an understanding of my experience.

**MR WALSH:** Do you mind if I just ask you a question as you go along?

**MS GAILE (BCA):** No.

**MR WALSH:** Is your vision impairment stable now?

**MS GAILE (BCA):** It is. It was diagnosed when I was eight years old but it slowly deteriorated until I was about 20 and then it has pretty much stabilised. Just a little bit about Blind Citizens Australia: Blind Citizens Australia is the national peak consumer representative organisation of and for people who are blind or vision impaired.  We have over 3000 members Australia-wide, so we speak on behalf of people who are legally blind or have severe vision impairment which impacts on their ability to attend to their daily life.  Blind Citizens Australia was provided with some funding to consult with our members specifically over the National Disability Insurance scheme, so we were very pleased to receive that funding, because it really has enabled us to do what we think is a pretty comprehensive consultation with our membership across Australia.

The consultations were really to gauge our members' perceptions on the nature of the report.  In total we've conducted 13 face-to-face forums throughout all of Australia, in every state and territory, and six teleconferences; often people who are blind and vision impaired can meet over a teleconferencing facility, because sometimes mobility can be a constraint to actually getting to a physical venue.  Our final consultation is actually taking place today in Perth, where we have 30 people.  I hope that what I'm about to put forward to you is a representative perspective of all of our members.

We will be making a written submission to this report on behalf of our members and we'll also be making a combined written submission with our deafblind colleagues from the Australian DeafBlind Council and our deaf colleagues from the Deafness Forum, both of which are consumer based organisation, and the combined submission will be from the sensory impairment sector or perspective.

My comments today are going to mainly focus around the core activities outlined in the commission's report, around the issues of mobility, communication, and self-care as they relate to blindness or vision impairment, because I think there is a misperception in the report, but also in the community in general, about what the constraints to mobility, communication, and self-care are for someone who is vision impaired as compared to someone who has perhaps, say, a physical disability. We can easily imagine what self-care might be for someone with a physical disability, but it's possibly not as explicit about how a person who is blind or vision impaired might need support, assistance, advice, guidance, training around self-care.

One of our concerns that our members commented on is that the model, the NDIS model as proposed in the report, isn't really a neat fit for people who are blind or vision impaired.  Under the proposed model there're concerns about what is the real cost of blindness and vision impairment.  An example of this is, the aids and equipment that people who are blind or vision impaired use are not currently funded through government funding, other than the job access program, which funds adaptive technology and workplace accommodations for people with disabilities.

Just to give you an example, this BrailleNote device, a braille note-taking device on which I'm reading my notes today, is a government-funded piece of adaptive equipment which enables me to attend to my work. I perhaps would not be as effective as I think I can be with my day-to-day work practices if I didn't have a note-taking device which is a word processor, a calculator, a calendar, it's the way I access the Internet, it's the way I keep my diary, I have an alarm on it so I can keep my appointments, et cetera. It has audio output and braille output, so it enables me to access information in my preferred format, which is actually braille.

**MR WALSH:** If you don't mind me asking, Robyn, how much does that cost?

**MS GAILE (BCA):** This tiny little thing is $8000. Once I left it on a seat in Byron Bay and nearly died. But it was Byron Bay; I got back there an hour later and it was still there. This kind of equipment gets upgraded relatively regularly too, so if you're in the workplace you can also access funding to enable it to be upgraded. But, interestingly, if you weren't a worker, you're not eligible for any government funding to pay for this kind of adaptive technology.

I would argue that there are applications to a note-taking device for a person who isn't in the workforce. This is my equivalent of a notepaper and pen; how many sighted people would operate in the community with no method of ever writing down a message, with no method of keeping a telephone book, a contacts list, with no method of being able to communicate via email and all the other social media strategies to their family and friends. Even though there are state based aids and equipment programs, for the most part - well, I have not heard of a blind person ever being able to access state based aids and equipment funding to purchase a note-taking device.

**MR WALSH:** Are there any schemes you know of in other countries that you can refer us to?

**MS GAILE (BCA):** I don't know specifically, but I have heard that especially Germany is a really good example of people who can access the aids and equipment they need, regardless of what phase in their lifestyle cycle they are, whether it be education or employment, but I can't name it. I can certainly look into it and forward that information to you. I've bought my white cane up to the desk even though with my level of vision I was able to find myself to this seat; however, I did rely on my colleague from Guide Dogs NSW to give me a verbal orientation to this room, so that I would know where to walk.

But I've given this example - why I've got my white cane here - because my reading of the report says that the white cane wouldn't be funded through an NDIS, because currently the $6.2 billion costing of what disability services costs is not inclusive of the non-government funded services provided by blindness agencies. For the most part, blindness agencies provide a white cane free of charge, to loan to people who are blind or vision impaired. They don't all do so, but for the most part they do.  So I thought that was nice little example of something that may actually be a challenge under an NDIS environment.

**MR WALSH:**   Maybe I can just clarify that before we go on.  The way in which the costing was done didn't restrict itself to government-funded services.  It used the latest survey of disability, ageing, and carers - which we don't have full details of, but to the extent we did have details of it.  Under that survey there are questions around, "Do you need aids and appliances?  Do you use aids and appliances?  If you do, what types of aids and appliances do you use?"  So that was the main source of data that was used to estimate the need for aids and appliances and I would imagine that white canes would be included in those.  We'll go back and check, but my understanding is that they would be.

**MS GAILE (BCA):**   I know we don't want to get to the minutiae of really itemising things, but some little daily living devices that a lot of blind people would rely on are like a liquid level indicator that you put in your teacup or a cup where there's hot water and you put it on the lip of the cup and it will beep when the water level gets to the bottom of it.  It's only a cheap gadget, but people who are blind or vision impaired need to purchase those.  Sometimes what people purchase out of their own funds they might not even put in the category of aids and equipment that they use.

**MS SCOTT:**   This does raise an interesting issue.  We did have someone from, I think it was Guide Dogs Tasmania, show us a range of items, Robyn:  relatively simple magnifiers to a more complicated device that sort of gauges where you're holding your hand and so on.  We now, I hope both of us, have quite a good education as each group presents to us about the different aids and appliances.  In the report we wanted to keep it on a page, so we wrote down, "Aids and appliances (including artificial limbs)," because we had a particular question about artificial limbs, so we didn't go and specify everything down.

There is an issue though.  An interesting question about, how expensive does a piece of equipment need to be before the government has to provide it; is it every piece of equipment; is it every replacement battery.  It's an interesting question.  I agree with you that if you wrote everything down, I'm sure that it would add up to be a considerable amount of money.  On the other hand, think about the government administration associated with ticking off a box related to a small purchase of an item.  That's why we quite likely individualise funding package arrangements, so that some people would get their funding package and they would decide what purchases, what the relevant items to purchase are.

Of course then, as we discussed this morning about tier 2, there are existing organisations that provide a range of services and easier referrals and relatively low-cost items:  should they continue to operate like that; would they like to operate in a different arrangement; where would they like to see themselves positioned in a new environment. So we'd welcome your comments on that when it comes to your written report.

**MS GAILE (BCA):** Interestingly on the subject of individual packaging, our membership was really mixed on how happily they would embrace it. A lot of members thought, "Yipee, yoohoo." I'll get to the issue of the age cut-off later, but many of our older members said that, if they had individualised packaging, there were four key services that they said they would purchase from that individualised packaging, which I thought was really interesting. It was personal reader services, because many, many people live on their own. Especially if you're older, if you don't have proficiency in the use of adaptive technologies to enable you to read printed material, and you may or may not be close to your family and you may or may not have a good relationship with your neighbours, who you trust to read your bills and things to you, if you purchased a personal reading service, you might have greater control over that.

The other thing that people said they would purchase is a driving service. Getting from point A to point B sometimes taxis you can't trust to drop you off at the right place, et cetera, so if you had a personal driver who you could purchase the services from, people said that they would love that. The third thing was adaptive technology training, because across Australia there's not a consistency of delivery of blindness-specific adaptive technology skills training. We did our Tasmanian consultations two weekends ago and the vast majority, especially people from Launceston, said that they would purchase adaptive technology services. I've completely forgotten what the fourth thing is, but when I remember I'll let you know.

**MR WALSH:** It would be good if you could let us know. That's really good information for us in trying to get a better handle on what support needs would look like. If you can think of the fourth one, that would be great.

**MS GAILE (BCA):** I've just thought of it: mobility services. We've got two agencies, who've spoken previously, who provide mobility and orientation services. However, again, depending on where you live in Australia, you will inconsistently have access to that service. That is one of my concerns, this notion of having greater choice - because you can package up the care and support that you need - on the one hand, is a fabulous notion, and, from a consumer point of view, very appealing. But it potentially is a false economy, because - especially if you live in northern Australia, or rural and remote Australia - there currently is no choice, and under an NDIS environment there still will be no choice.

There will be no provider in outer-western North Queensland or in the Northern Territory, or even northern WA, who will be able to provide you with an orientation and mobility service in a timely manner, regardless of whether or not you're in control of the funding that's allocated to you.  So that is one of the concerns that some of our members also raised.

**MR WALSH:**   What would happen at the moment for people living in those areas?

**MS GAILE (BCA):**   What happens for those people is one of two or possibly three things.  They are put on a waiting list with a service provider, who may not provide services on that region but will come to that region on a semi-regular basis, maybe once every two months, and so they wait till they get a waiting list happening, and then once they have got enough demand they will then go and meet that supply.

They travel interstate - we actually had an example of one of our Launceston members who with her own money went to Victoria, Guide Dogs Victoria, and purchased a live-in service where she was trained in daily living skills, and then went back home and implemented it.  The third option is they do nothing.  They do what my father in Queensland, who is also legally-blind, does, and that is sit at home and read talking books, and wait for someone to take them out.  As you can imagine, from a consumer perspective, we really don't want that to be happening.

**MR WALSH:**   So on the wait for someone to take him out one, you wouldn't need a qualified person to be able to do that.

**MS GAILE (BCA):**   No, and under an individual packaging environment, he could potentially purchase in.

**MR WALSH:**   So there may be some benefits in those areas then.

**MS GAILE (BCA):**   That's true, yes.

**MS SCOTT:**   Let's just go back to your use of the phrase about greater choice but false economy.  Maybe I would characterise it as greater choice but not perfect; you know, the tyranny of distance still exists.  With your device, you have got access to the Internet, I think you said.  We met someone at the Melbourne hearings, a person who was deaf/ blind who made the point to us that because she wasn't working she wasn't eligible for a $3000 device that would have enabled her to be able to effectively access the Internet, get text messages, all sorts of things.  I'd have to say that, for the want of $3000, it seemed a remarkably limiting decision that she wasn't able to access things.  No-one should have false hopes that this is going to overcome all the problems that exist, but, to the extent it does offer greater choice and assists many, many people, I guess that could make a difference.

**MS GAILE (BCA):**   Yes, and so potentially, in an NDIS environment, someone who isn't working who could package up their supports has that ability to purchase in the adaptive equipment that they would need.

**MS SCOTT:** Yes. To the extent that that is a whole lot cheaper than the cost of a translator and the person has so much more community access and as a result a higher level of independence, I would have thought it was effectively a no-brainer.

**MS GAILE (BCA):** Yes, and that is why, especially with various state aids and equipment programs, there is such a limiting criteria that, frankly, if you were a creative accountant you could find your way around it, by grant application, but many people aren't creative accountants. I would argue that under many of the state aids and equipment programs you could say that this braille device is a daily-living-skills aid. You know, I came from Melbourne today, I wrote my flight details in here, I had phone numbers and the address details, I corresponded with the PC office about my times, et cetera. It enables me to be effective and efficient on a daily basis. I keep recipes in here, all my accounts and files, all the numbers that we all have, PINs and things, are all kept here. So it's a daily living device as much as it's a workplace aid.

In terms of eligibility, the report says that the NDIS would only cover 360,000 people. Statistics that we have from the Australia Bureau of Statistics vary from between there being 300,000 and 400,000 people who have severe vision impairment. So there are some concerns about who of the population of people who are vision-impaired would be counted. I won't deliberate over that, because, having witnessed the two previous pieces of evidence, you have already suggested that Guide Dogs NSW and Vision Australia and BCA put together some wording around eligibility.

**MS SCOTT:** Just for the record, because there will be people looking at your transcript, I think I should correct you slightly, or clarify, that the scheme covers more than 360,000 people. It's proposing that it covers all Australians and that there is just a differentiated level of supports, and it's the tier 1, tier 2 and tier 3. I'd be interested whether you think you could advise us on whether the 400,000 would need an individualised package and would meet the eligibility criteria we have set out in the draft or whether some of those people would be better suited to a tier 2 type referral. So I'd welcome your advice on that.

**MS GAILE (BCA):** I do stand corrected, because that 360,000 figure is the tier 3 category.

**MS SCOTT:** That's correct.

**MS GAILE (BCA):** Yes. There are a good many people who are vision-impaired, in fact probably the majority, who require episodic access to blindness-specific services. I think, rather than measuring based on whether or not you're totally blind or partially sighted or have low vision or no vision, or whether you've just acquired or you haven't acquired your vision impairment, it's about the level of functioning you have with your condition.

Because I know Kevin Murfett and Michael Simpson pretty well, I'm going to say something that I haven't asked for permission from them to say. They're both totally blind. I have some useable vision. Michael is adept with managing his environment, and what have you, but if someone of similar age to Michael acquired their blindness today they would have much greater need for services than Michael does today. So it really is around the functionality that is caused by your vision impairment.

**MR WALSH:** Robyn, would that be a learned thing. So over five years or so, would someone who became totally blind late in life learn to manage their environment?

**MS GAILE (BCA):** Everyone is an individual, so you can't necessarily make a blanket statement; but generally, yes, when you first become blind, if you access the right services straightaway. The rehabilitation services you might encounter would be, as Michael did speak about, orientation and mobility. So learning how to navigate your way in any environment. But not just how to navigate, how to problem-solve. The summary of what a mobility instructor does is three things, they help you to learn: "Where am I right now?" "Where do I want to go?" "How am I going to get there?" When you have lost your vision, you need to come up with new strategies about how you would do that.

It's interesting that what I call independence sometimes a newly blinded person doesn't. When asking a stranger a question, as I did when I walked in today, "Where are the toilets?" I think that's independent, because I asked for where they are and I asked for instructions how to get there, and then I made my way to the toilet. So I think that's being independent. But sometimes a newly blinded person would say, "The fact that I had to ask and couldn't see the signage and there was no way to get me there independently means I'm not being dependent." So I think a part of the rehab process is learning to be comfortable with what you call dependence and independence as well. Does that sort of give you a notion of my argument?

**MR WALSH:** Yes.

**MS GAILE (BCA):** I have jumped around a bit, so I'm just going to move forward. One of the big fears that many of our members raised during our consultations was that in an NDIS world if block grant funding was removed the outcome potentially might be that services they received for free or low cost would now have a cost; if you weren't one of the tier-3 360,000 people, a service which previously had no cost to it may now be a fee-for-service cost, and, if you're not an NDIS-covered person, you're now having to incur a cost out of your disability support pension, your sole income, that you didn't have to before NDIS came through.  That was a great fear that many of our members had.

**MR WALSH:**   I think we have taken that on board, yes.

**MS GAILE (BCA):**   Just on the issue of age, the age cut-off, just one comment I'd like to make is that people aged over 65 who therefore do not qualify for an NDIS may not receive the same services as their counterparts who are under 65.  Our concern is that that is counter to the Productivity Commission's statement that no person would be worse off under the introduction of an NDIS.

An example that I have here - a really small case study - is if, say, Susie, 25, becomes blind, sudden vision loss, what she might need is orientation and mobility skills so she can move around safely and with confidence; she might require some adaptive technology skills training so that she can have a reading and a writing tool; if she has got any remaining useable vision she might require some training, which is usually delivered by an orthoptist, around using her residual vision to best effect; she might need braille training - there's a range of blindness-specific services she might need.

Now, if Betty, who is 67, suddenly loses her vision, she needs exactly the same services as Susie does, regardless of her age. They have both suddenly lost their sight, they need some of these skills training in order to feel confident and safe in the world.  Perhaps Susie might then also need some vocational training so that she can maintain her current employment or change the nature of her employment if that employment not something that a person with her level of vision could do.  I have now covered it all, because your questions covered the rest of my points.  I apologise for it being a bit lengthy.  I'm happy to respond to any of your question.

**MS SCOTT:**   I thought, Robyn, it worked out very well, because we were able to ask our questions as we went.  It's very encouraging that you have had this consultative process going on.  It gives the sense that there's a wide network out there commenting on the report and feeding ideas through.

**MR WALSH:**   Yes, that was good.  Thanks, Robyn.

**MS SCOTT:**   Thanks, Robyn, very much for coming along today.

**MS GAILE (BCA):**   Thank you.

**MS SCOTT:** Because we had the earlier break, we're not having morning tea now. There's probably a sense of disappointment, but I'm going to be a disciplinarian and just move on. Now I invite to the table Barbara, please. Thank you for coming along today, Barbara. For the record, could you indicate your name - I think you're representing yourself - and then if you could make an opening statement, please.

**BARBARA:** My name is Barbara. I have many years experience working in carer support. I come today as an individual, because trying to get permission at the moment to be here in an official capacity would be probably pretty impossible. I applaud the work that has gone into the report. Having been in the privileged position to be able to hear from both commissioners and the synopses at two recent forums, I have to bring the voice to the table for those who are not included.

**MS SCOTT:** Just to clarify for John and the audience, you mentioned earlier that you have been following the aged care inquiry and also this one.

**BARBARA:** Caring for Older Australians and this one, yes.

**MS SCOTT:** So Barbara has got one of the advantages of following both. So just to clarify that.

**BARBARA:** Yes. In my daily work I come into contact with carers across the caring spectrum: mental health, disability, illness and frail aged. What my concerns would be and I would bring to the table is that, please, the reports must reflect care for all Australians, regardless of their illness or disability. The cohort that are missing out on both the reports at the moment would be the palliative care, significantly, but I also note in the report that there is some discussion around mental health, and mental health and disability.

Serendipity is the name of the game in my business. In the past couple of weeks I have seen a lot of instances where people have an intellectual disability together with a mental health condition, and they're missing out on care, access to residential support, those sorts of areas. Another issue that we have in the community is with neurodegenerative disease. I have got a seven-year-old, Harry - and I think Harry's dad has actually written in, I asked him to - and he has been palliative for four years, and they get no support in the community.

**MS SCOTT:** Barbara, can I just hold you up a little bit? Don't worry, we'll give you enough time. I know you can't officially say which part of the health sector you're from, but - - -

**BARBARA:** I work under the Department of Health in the area of health service, but I won't name which area of health service.

**MS SCOTT:** No, that's all right. Fair enough. I want to be careful about protecting you as well.

**MR WALSH:** Can you say whether your role is community care or kid care, Barbara?

**BARBARA:** I manage a service called carer support and it spans both areas.

**MS SCOTT:** Okay, so you're at this very interesting interface issue.

**BARBARA:** I'm totally at the interface.

**MS SCOTT:** Would you feel comfortable if we asked you a few questions just for a little while?

**BARBARA:** Absolutely.

**MS SCOTT:** We have had other evidence in another state talking about palliative care, and you would have seen from the report that sometimes we fall into the trap of thinking that these services exist because people refer to them every now and again. We had someone presented to us very compelling evidence from a Brisbane hearing - so you might want to go back and have a look at this on this web site when it becomes available - about someone whose husband had a degenerative neurological condition - - -

**MR WALSH:** Multiple system atrophy.

**MS SCOTT:** - - - and explained that over the course of the six years they received very, very little support and didn't seem to fit into any particular category. When we said, "But what about palliative care?" her husband only became eligible for palliative care when he was in the last three months of life and, of course, the question was, you know, which six-year period was he in the last three months of life. So rather than going to the individual case of a seven-year-old with a degenerative disease - just pause for a little bit. Can you tell us about what palliative care services exist in New South Wales or in your region?

**BARBARA:** We need to put the definition - and this is the heart and the crux of palliative care. Palliative care within the acute sector is the medical care, and it's the nurse that comes in with a syringe driver, checks room management, medication, pain management. They may come in for one or two hours, twice a day, three times a day, something like that. They will come in, go out, come in, go out.

**MS SCOTT:** So it's clinical care.

**BARBARA:** It's clinical care. When we're talking about care in the community, it is about the person because we need somebody there 24-7. It's about the person who is there 24-7 to give the sips of water, to help with adjustments, all of those sorts of things. That is the component of palliative care that does not exist. I don't think actually, honestly, it exists across Australia, but I'm not an expert across Australia.

**MR WALSH:** At what point, can I ask - and that would vary enormously from individual to individual - does the person go from that community non-care into acute clinical care? Is there a protocol or is it up to the doctors, is it up to bed availability?

**BARBARA:** They can be plugged into what is seen as palliative care and be plugged into acute palliative care for that - Harry has been plugged into an acute palliative care team for four years, but they get no support in the home, so dad has to be at home, has given up work and they get no respite. When we talk about going to the Commonwealth Care Respite Centre, they'll say, "Yes, we'll help the family," but when you really drill down, what is that help for the family? Two occasions of service. You're sitting there and you say, "That's great. This week, how many - which nights?" "No, no, not this week, not even in a month." Two occasions of service, perhaps three, in a year.

**MR WALSH:** I just want to understand this a bit more clearly. So there are programs - until next year there's the HACC program, there's the EACH program and so on. Those programs don't provide any support for community based - - -

**BARBARA:** EACH does, but for the northern Sydney region we had four EACH packages in a year and that's four people.

**MS SCOTT:** You mean four for all of north Sydney?

**BARBARA:** Four for all of northern Sydney. So we've got to be careful with the numbers but - you see, you could be waiting for a year.

**MR WALSH:** I guess our point is that this is a responsibility of a system that does exist but what there is is a funding shortfall.

**BARBARA:** I know from where I work we're going to drill down on the definition of palliative care in the next few weeks. The definition of palliative care has not been decided and has not been debated long enough. So the deprivation of social support, care, respite, breaks for the carer. Carers very often don't get carer payments, carer pensions, they're not eligible. That's where we need to look and that's why I come back to - we need to be looking at these social reforms as across Australia, as across all people who have an illness disability regardless. I'm sorry it's thrown my presentation out.  Do you want me to get back on track?

**MS SCOTT:**   Okay.

**BARBARA:**   I think I have stressed enough to include palliative care and mental health.  Within the assessment component - I think that's on page 50.  The assessment for carers, I wholly support that.  I think that's very, very necessary to be included.  But I would also like to stress that when assessments are done that they're done once and they are then shared.  We waste a huge amount of money in the community by assessing, reassessing and reassessing again.

With the carer payments and disability pensions, I would encourage that they be included as part of NDIS because I don't believe that Centrelink are really experts in disability in particular, and I see too many people who have the definition miss out, not eligible.  But hand in hand with that I would really encourage that we actually look at which family member has to give up work.  I've got a lady in the community at the moment with two highly disabled children.  Her husband receives $67,000 a year so she doesn't get the carer's pension.  She gets the allowance, the $90 a fortnight, but not the - - -

**MS SCOTT:**   Because of the - - -

**BARBARA:**   Because it's over $65,000 a year.  In terms of the starting-off points, I would really encourage that we do look at older parents as a priority group for starting with, and the combination to be the priority in that cohort, and then the management and the conversations around that accommodation and all of the guardianship issues to be a very high priority.  That's certainly identified for me.  I would also like those to be included who don't currently get support.  Little Mikayla, who's six, doesn't get VDQ overnight - - -

**MS SCOTT:**   You can't use abbreviations.

**BARBARA:**   Sorry, ventilator dependent quad program for oxygen overnight.  She was premmie and requires oxygen overnight but there's no care.

**MS SCOTT:**   So she can get oxygen but she can't get care?

**BARBARA:**   She can't get oxygen either.

**MS SCOTT:**   She can't get oxygen either?

**BARBARA:**   No, but she requires - there's no funding.

**MR WALSH:**   Is she living at home or in hospital?

**BARBARA:** She lives at home. She's slow to start but goes to school.

**MS SCOTT:** How do her parents afford the oxygen?

**BARBARA:** She only has one parent. There's very tragic circumstances surrounding her mother.

**MS SCOTT:** How does she afford the oxygen?

**BARBARA:** They don't. It's some creative - - -

**MS SCOTT:** Yes, I see. That's all right.

**BARBARA:** They don't. The other issue there was that there was no support for getting this little tot up in the morning, getting her dressed, transport to school. Dad works in a trade environment so needs to start at 6 o'clock a long way away from home, and we couldn't get any support in. So there's some situations in the community. I'm happy to elaborate.

**MS SCOTT:** I think if your submission - I know you do this in your own time and I'm very conscious of that but, Barbara, you seem to be at the very difficult interface of one of these people that has to juggle different buckets and use creative methodology from time to time.

**BARBARA:** Sometimes I don't; I simply don't.

**MS SCOTT:** Actual examples of the paucity of service would help us. You started off with, you'd like to see all these distinctions removed. You may have heard our earlier comments that if the scheme included everything it would be so big, unwieldy and expensive - - -

**MR WALSH:** Can I just put some context around this for the record.

**BARBARA:** I totally understand.

**MR WALSH:** The total budget of the Australian health system is - I think the latest information is somewhere between 110 and 120 billion dollars a year.

**BARBARA:** Yes.

**MR WALSH:** The total budget of the disability system is $6 billion a year.

**BARBARA:** Yes.

**MR WALSH:** So to expect the disability system to take on some of the notional responsibilities of the $120 billion, the orders of magnitude just don't add up. So we need to be realistic about what this scheme can achieve.

**BARBARA:** I totally concur and I totally agree with that, but consistently the group of people I'm speaking about miss out now, have missed out and will always miss out and it's inhumane.

**MS SCOTT:** Yes, I agree, it's inhumane. You would have seen some comfort in the report that some of the groups like the older parents, the accommodation need - - -

**BARBARA:** Yes.

**MS SCOTT:** We specifically indicate that there should be a high priority area. We've talked about an individualised package based on need and so on.

**BARBARA:** Yes.

**MS SCOTT:** Is there aspects of the report, besides the aged care interface, that you have real concerns or worries about?

**BARBARA:** The fact that palliative care is not on the radar, and the debate around mental health.

**MS SCOTT:** Okay.

**BARBARA:** They're the two significant components.

**MS SCOTT:** Well, on mental health, because we asked that question very explicitly and because we did struggle with it and we advanced that maybe people with psychotic - very severe conditions should be included, we'd welcome any of your written advice on those areas.

**BARBARA:** Okay.

**MS SCOTT:** If you can think of a solution between now and 30 April for the aged care interface which doesn't involve everything collapsing into each other, I'd welcome it too, but I do think we need to be realistic.

**BARBARA:** I totally agree.

**MS SCOTT:** I'm interested in your role. It seems that there is a recognition at least that somebody needs to help someone navigate between them.  Does it work?  Does your role work?  Does the idea of joint responsibilities ever work in your mind about protocols or actually saying, "Look, here is an individual, Mikayla, or the seven-year-old child with a degenerative disease."  Is it possible within New South Wales' arrangements or from your experience that you could actually say, "Right. This person has got clinical needs, they've got home support needs, they may well have education needs."  Do you think it's within the capacity of human nature that individuals like you could formulate packages of support and get people to cooperate to get truly good service for individuals or is it just too hard?

**BARBARA:**   No, no, absolutely not.  I've got one motto in life:  never drop a carer, and we'll never drop a caring situation.  Is it possible?  Absolutely, yes.  But does everybody need it?  No.  The cases that end up with me are the very pointy end, the very complex, the very difficult.  I'm there for the time until I anchor it into something else, however long it takes me to create that or make it happen.  Does it rest with one organisation?  I see some pluses and some minuses.  At the moment the problems we have got is where people interpret and work within parameters and boundaries.

**MS SCOTT:**   Yes, that's right.  The problem is the very strict interpretation and the very strict rules in which they have to operate.

**BARBARA:**   Yes, and the dysfunctional tokenism of $80,000 packages.  $80,000 for social support for frail, older men in a population of 830,000 people?  You can use the dysfunctional tokenism.

**MS SCOTT:**   I'm still getting over the four packages for all of north Sydney.  Just on that, I know each package is orientated more towards the aged care.

**BARBARA:**   They are for the aged, yes.

**MS SCOTT:**   But how many people would you effectively see that could do with an EACH package because of their non-age related disability?

**BARBARA:**   We tend to go for the attendant care package in New South Wales, so that's the motor neurones.  That's been really beneficial since that's been created in the last couple of years.  Attendant care actually provides more hours of service than EACH does.  Once we get it in place it tends to have positive outcomes.  At the moment we're just trying to navigate through to get to a level 2 on an attendant care for someone with motor neurone, so that can be - - -

**MR WALSH:**   I think again in context, I don't know the exact numbers, I think - there's certainly less than a thousand, maybe six or seven hundred attendant care places in New South Wales.

**BARBARA:** Yes, that's right. In terms of the actual numbers that I see, there's a significant number that I would prefer to see on the attendant care that are not getting it. That's the mums with the broken backs, the significant health issues.

**MS SCOTT:** This is a hard question but you're at the coalface, and I'm not: what sort of increase in the existing level of New South Wales funding would it take for those most pressing in need to get the attendant care they require? Would it be a 10 per cent increase in funding?

**BARBARA:** That's a hard number to put on it. But with the clients that I've got at the moment - and again it's that kind of serendipity - I think I've probably got 10 kids or 10 adults who need to have a higher level of care. They're getting two hours, three hours of respite a week. So I've probably got 10 just within my region that I'd like to see some form of attendant care allocation; in other words, a higher degree of care or respite accommodation.

**MS SCOTT:** So they're getting two hours. What would you assess is the number of hours that individual and their family should really receive? If there was a needs based on reasonable need - - -

**BARBARA:** 20 to 25.

**MS SCOTT:** Right. Okay.

**BARBARA:** But I can go away and really analyse that and work it up for you, if you want.

**MS SCOTT:** That would be useful but I don't want to put you to undue work. Barbara, I know we are running out of time and we probably didn't do things in the order that you might have wanted. On the other hand I do think it was a very useful exchange.

**BARBARA:** Sure.

**MS SCOTT:** Would you be comfortable if we left it there?

**BARBARA:** Yes, absolutely.

**MS SCOTT:** Thank you.

**MS SCOTT:** I now welcome to the table the Spinal Cord Injuries Australia, please. Good morning.

**MR BRICE (SCIA):** David Brice, Tony Jones and Greg Killeen.

**MS SCOTT:** Right. Over to you.

**MR BRICE (SCIA):** Thank you. We're from Spinal Cord Injuries Australia which, as the name suggests, we represent the interests of people with spinal cord injuries and provide vital services for them, and also people with similar disabilities. We've been going for 40 years; initially known as the Australian Quadriplegic Association, and in more recent years known as Spinal Cord Injuries Australia.

I must say that when I read about this proposal for the National Disability Insurance Scheme I was very happy - we all were - because we know that this scheme hasn't been working, disability. Not many people with disabilities or with severe disabilities do achieve a proper quality of life through various reasons, and the Productivity Commission has recognised some of those reasons in the report. One of the reasons of course is that there's been a hodgepodge of schemes that people have to try to work their way through, become eligible for, and have to be sufficiently destitute to qualify for. So there's a real need for a national, universal disability insurance scheme. We're very pleased with the report.

However, we then see that in fact the report suggests that we have two schemes: a scheme for people who had catastrophic injuries through accidents and, as a matter of fact - I just can't find what page it was on, but one of the pages there listed people who weren't eligible for the National Disability Insurance scheme and at the top of that list is people who receive catastrophic injuries through accidents. When I first read that I thought that's probably a bit discriminatory; if we're talking about a national scheme but we're not going to have people with obvious disabilities, severe disabilities - quadriplegia, paraplegia, brain injury, whatever - not eligible for the scheme. I thought that didn't sound right at all. So that's probably one of our major beefs and we'd be happy to discuss that further today.

**MR WALSH:** Do you want to talk about that now?

**MR BRICE (SCIA):** Yes, John.

**MR WALSH:** I think, by way of clarification, people who have sustained a catastrophic injury - "catastrophic" is an awful word, but it seems to have got into the popular vernacular - before the start of, what we're calling, the National Injury Insurance scheme would be eligible for the NDIS. So I think there's no discrimination there.

**MR BRICE (SCIA):** No.

**MR WALSH:** People who sustain a new catastrophic injury effectively would be covered by a parallel scheme, which would have the same or equivalent entitlements to the NDIS. There's no intention of discrimination; indeed, I think we've got full coverage. The point is that, because there are existing funded schemes for catastrophic injury which are governed by a total of about 32 pieces of state legislation, the practical approach we took was to expand those entities rather than to attempt to wrap them up and put them all into a disability insurance scheme.

**MR BRICE (SCIA):** They're not in all states though, are they?

**MR WALSH:** All states have compensation entitlements for people with a catastrophic injury, through public liability, workers comp.

**MR BRICE (SCIA):** The courts, yes; common law.

**MR WALSH:** Or medical indemnity.

**MR BRICE (SCIA):** But not all of them have a scheme like our long-term care and support scheme.

**MR WALSH:** No, they don't. They're all working towards it and they all have a funded system already in place.

**MS SCOTT:** We are recommending that they all move to a no-fault arrangement for care and support, so they'd start to look more and more like the new New South Wales scheme.

**MR BRICE (SCIA):** Yes.

**MR JONES (SCIA):** The question might be two different levels of administration for essentially the same disability; you'd have one in one scheme and someone who is filed with an equal, the same level of disability in the other scheme.

**MR WALSH:** I think that's right. So you could have someone, like all of us, who've had an injury prior to this being in the NDIS and people who sustain a new quadriplegia being in the new NIIS. That's right. The only reason that's the case, that we're recommending it, is probably a practical issue of what's most feasible. We were asked to look at the feasibility of a National Disability Insurance scheme; the feasibility of unwinding all of the state schemes is a consideration.

**MR KILLEEN (SCIA):** Maybe you could expand the New South Wales Lifetime

Care scheme to be the NDIS, rather than the reverse way around and having a segregated scheme. What would happen if there was no TAC or no New South Wales Lifetime Care scheme as we speak; how would the NDIS operate then?

**MR JONES (SCIA):** I notice you pose the question yourself. The PC poses the question of, why an NIIS is needed at all; compulsory insurance providing third-party cover could be removed as a possibility of merging the two somewhere down the track.

**MR WALSH:** That is discussed in one of the later chapters, yes.

**MS SCOTT:** Greg, I want to go to your question; it's a good one. If there's a good arrangement in a state, why couldn't it be expanded to include absolutely everybody. We did actually explore that with some of the people that operate those schemes, and their eyes widened and they started to look pale, because for them, at the moment, even the large schemes like the TAC deal with relatively small numbers. If you end up saying that people with intellectual disabilities, people who need support from birth, people who occur a difficult degenerative condition with all sorts of support needs, and they ended up saying, "This is not our area of expertise and how would we possibly expand to incorporate these things." Then the question is: people in the TAC who are currently there, what do you do with them relative to the new arrangements.

**MR WALSH:** The TAC has 3000 claimants under its management who have severe support needs. We're talking about 360,000, so it's a big jump.

**MR KILLEEN (SCIA):** So if the current scheme doesn't think they could manage that, then who would be managing the NDIS?

**MS SCOTT:** Because we are talking about having a national body with a regional framework - in some locations, like, let's say, Tasmania, we've heard that in Tasmania almost all of the services are now provided by non-government organisations. They have an assessment gateway and that assessment gateway is overseen by the government, but it's actually provided by NGOs as well. What we're suggesting changes is: who's eligible, the quality of care they receive - all sorts of changes there - but fundamentally it's about providing more people with more services by having larger funding.

Greg, the framework is there in some locations; not all locations. In some locations it would need to be reformed and improved. But you don't need a super-duper bureaucracy to run this arrangement, because people are going to be, in some cases, given their own package or they'll be able to nominate where they want to receive services from and it really is like a payments mechanism rather than a complex scheme itself. So it's true that you'd have to transform what exists, but I think it's a harder task to take an organisation that's only dealt with a very small population set with very specific needs than to bring together in a new way existing services.

**MR WALSH:** You guys clearly feel strongly about this and you should make a submission to us, putting out what you propose. One of the other things I think it would be useful for you to comment on and consider is that the existing compensation schemes, all of them around the country, collect premiums on a prospective or fully funded basis. So the amount of money that's paid for the New South Wales Lifetime Care scheme and collected each year as premium is put aside and that's the amount of money that's required to pay for the whole future lifetime care needs of a new entrant to that scheme. The TAC is the same and so is the MAIB in Tasmania.

Those schemes have investments of several billions of dollars locked up. It's not feasible that a full, national, 360,000-people scheme would operate on that basis. So to transition those state schemes would need some pretty careful dancing to work out how you managed, actually, the financials through the transition from state-owned billions of dollars, into a consistent, pay-as-you-go, unfunded, larger scheme. So there are some major feasibility issues around administration, legislation, and finance. You're not the only ones who have brought this up, so it's one that we need to consider. By all means, if you can put a submission in, that would be good.

**MR BRICE (SCIA):** Thank you. Just in relation to that, the NDIS, when I read this, it looks to want to include involvement by people with disabilities in the policy, planning, and development of supports. There's no guarantee that that policy would be part of the imposed state schemes. The Lifetime Care and Support scheme currently operating in New South Wales, I think that it has done well, but not every consumer of that scheme is happy with it. They may feel it is over bureaucratic, they're not listened to sometimes, and we'd hate that to go through to these other schemes which are supposed to be under the NDIS. We'd like the policies and aspirations in the NDIS to also operate in those state schemes.

**MR WALSH:** Yes, I understand that. I think there's no reason why that can't be the case and I think, if you spoke to the people in Lifetime Care, they'd probably say that they do try to have those aspirations. No scheme is going to be perfect and really I think that's a role for Spinal Cord Injury Australia to advocate actively on behalf of those issues. There is the advisory council of Lifetime Care that does have representation by people with a disability and by service providers. That advisory council was put in place for the very reasons that you're talking about.

**MR BRICE (SCIA):** Any comments from you guys?

**MR KILLEEN (SCIA):** Yes, I'd like to raise the issue about a couple of things: about the assessment process and about doing the assessment on someone's needs. I'm not really sure if there was a cap on the amount of hours that someone might receive and the type of assistance someone might receive. There's also the models of assistance. Apparently some people might get, under the National Attendant Care scheme or the Attendant Care scheme, it's up between 14 and 35 hours per week and some people in the community need that - possibly need more - but sometimes they need some kind of back-up support service.

So there's two parts of this: one is when they've actually got a service in place and there's a bit of a glitch in the system where someone's not available to turn up in the morning or turn up at night or whatever, there's really a need for a system where people have got some central-call back-up service where there's proper administration and someone can allocate assistance. Obviously, that's if you're using a service. If you've chosen individual funding and you set up your own service, that's something you need to be able to do.

Spinal Cord Injuries Australia operates an out-of-hours nursing service which runs between 9 pm and 5 am in the morning, seven days a week, and also between 11 am and 3 pm, seven days a week. So the out-of-hours support service only operates within the Randwick Botany municipality. It's a great model, because it really supports people to be able to live in the community, and that's something that I think would be - that and the out-of-hours back-up service certainly should be considered in service provision as well.

**MR JONES (SCIA):** Also within the assessment is this possible up-front fee of $500. I know as a possibility we don't think that's a - - -

**MR WALSH:** If you guys could make a submission on that, that would be very useful.

**MR KILLEEN (SCIA):** Currently not provided by the Attendant Care Program, it may be provided by services like Home Care New South Wales and other service providers. I'd like to raise the issue about equipment. With the equipment, I think it's fantastic that an NDIS would cover equipment, aids and appliances for people. There's just a couple of things I need to address, and that is establishing an understanding of what the demand is for the amount of equipment that is being provided currently.

I don't know if you've done the number crunching of what they provide each year, but what they provide doesn't necessarily equate with what the demand is. A lot of people don't put applications in because, historically, there's been waits of over two years, so they actually gave up on applying or, if they're younger people, they might have applied to a charity like Variety and all the different service clubs for assistance.  There's a whole bunch of other organisations out there who actually are providing equipment, where maybe the government should have been providing that equipment to support people live in the community.

**MR WALSH:** The cost estimate in the report about equipment doesn't exclude needs that aren't met, so it has an estimate of the number of people who need aids and appliances or equipment, what they need for - mobility, communication, self-care - and it estimates the cost required on a needs basis.  It doesn't limit itself to saying, "New South Wales pays $30 million a year for Enable, so that's what we'll put aside"; that's not the way it's been done.  It should at least, I think, cover the theory of what you've been saying.  Whether we've got the numbers right is another question, but any information you've got on that would be useful.

**MR KILLEEN (SCIA):** It's not just the one-off cost as well, there's the ongoing servicing and maintenance of equipment.

**MS SCOTT:** Yes.

**MR KILLEEN (SCIA):** As you're probably aware, if mobility equipment breaks down on a Friday at about 3 pm, and it's the out-of-hours back-up that needs interest as well.

**MR WALSH:** The other thing that would be really useful would be - you said it only works in the Randwick Botany area - but, I guess, the demand for the after-hours back-up service, what's your experience on how much that costs, what it requires, what are the implications if you tried to scale that across Australia?

**MR KILLEEN (SCIA):** The New South Wales Home Care branch in the Randwick Botany area is the only one that offers or operates a pseudo out-of-hours back-up service.

**MR WALSH:** I'm well aware of that.  I don't live in the Randwick Botany area, but I'm well aware that there's no after-hours service elsewhere.

**MR KILLEEN (SCIA):** Yes.  Also vehicle modifications.

**MS SCOTT:** Sorry, just go back to that after-hours service, because I think you mentioned it last time you presented to us, and I think John made the same remark last time; that it was constrained, even in service areas.  Is that just a funding issue? There's no fundamental reason why a back-up after-hours service couldn't be more generally available.

**MR KILLEEN (SCIA):** We're all for it.

**MS SCOTT:** All right, but it's just a funding issue?

**MR KILLEEN (SCIA):** Funding and administration, exactly right.

**MR JONES (SCIA):** It's not necessarily that well run within the Randwick Botany area either.

**MS SCOTT:** No, but it's a model that something could develop out of.

**MR WALSH:** I think you guys are being a bit modest. The services in the area that they're talking about are a function of the fact that it's where Spinal Cord Injuries Australia has been for 40 years.

**MR KILLEEN (SCIA):** Prince Henry Hospital is where the spinal injury unit was and we had a combination in the area, and the major branch for Home Care has all moved into the Maroubra area, so there's a high density of people just within the area so it's got a back-up service. But it needs to be proper administration right across the state, all country as well, and also the out-of-hours for the emergency back-up that Spinal Cord Injuries Australia operates as well.

**MS SCOTT:** That's one of your key points, Greg, that people may have an individualised package under this new proposal, if the governments accept it, but it doesn't really help them if it turns out the service provider doesn't provide an after-hours service. Okay.

**MR KILLEEN (SCIA):** Ironically, if you're a government funded NGO there's a requirement to provide an out-of-hours back-up, but if you're actually the funding body to provide the service itself, they don't provide the back-up.

**MS SCOTT:** Yes.

**MR KILLEEN (SCIA):** Work that one out. Vehicle mods.

**MS SCOTT:** Vehicle modifications, yes.

**MR KILLEEN (SCIA):** There's a real need for vehicle mods. I think there might be one or two states or territories that might provide vehicle mods. I think there's a real need for the provision of vehicle mods. It's not really interest.

**MS SCOTT:** We've got it in the list of things; that's fine.

**MR BRICE (SCIA):** One of the other points that I was glad you brought up in the draft report was workforce issues.  I think that if this is introduced it's going to have an impact on demand for care services, a greater demand, and at the moment some organisations have the funding but they can't find people to carry out personal care work et cetera.  So this is only going to exacerbate the issue.  I think that's an issue that really needs to be looked at when this is introduced because you may have people saying, "Beaut, I'm eligible for this now," but they can't find any workers.

**MS SCOTT:**   There's a chapter in the bigger reports.  Chapter 13 seeks to address that.  One of the things is we do think that because there will be increased demand for attendant care services, we are expecting that one of the responses will be that wages in that area for some people will increase and that that will draw people into that service.  We've talked about more flexible arrangements in terms of shift work.  We're also talking about people having individualised packages, so if they wished to they could hire people they know rather than having to always go through agencies, and so more flexible arrangements.

You may find that chapter 13 offers some solutions that you think have merit.  If you don't, by all means we're open to suggestions.  Surveys of existing attendant care workers say that they would actually like to increase their hours.  It's the limited funding that prevents them working longer.

**MR BRICE (SCIA):**   Okay.  I'm glad you're onto that.  Any further comments from you guys?

**MR KILLEEN (SCIA):**   I would just like to make a comment about assessment.  I'm currently aware of a situation in South Australia where people try to do an assessment or an application for a support service, they require a diagnosis.  If the person has a disability, a degenerative condition, it's undiagnosed.  So although physically she has difficulty providing her own personal care and support, because technically she hasn't got a medical diagnosis, she's not eligible to apply for disability support to Disability SA.  She's under some other program and she gets two hours a week, which is two showers a week.

We can't have this situation where someone has obviously got a disability - I mean, they're not feigning it - but the assessment is, "No diagnosis from a doctor or specialist, sorry, you can't apply."  It's just outrageous.

**MS SCOTT:**   We've had other cases like that presented to us as well; people that are clearly suffering a severe degenerative condition with muscular wasting but doesn't seem to fit a particular category.  You would have seen from our eligibility criteria we talk about functional need, so we're not talking about diagnosis.  Clearly medical reports will be important to the assessment process to see what's suitable but hopefully we've addressed that one sufficiently well, Greg, but it's good to be reminded that it's easy to draw a boundary and find that someone just doesn't fit into the category.

**MR JONES (SCIA):** There's also the mention of possible self-assessment. You get people who have spinal cord injury for a long time and generally have a good idea of what their needs would be. How would self-assessment generally work as opposed to just having an assessor come and have a look at an individual's needs?

**MR WALSH:** Tony, there is like a flow chart in chapter 5 which describes the process. If you're a quadriplegic of long standing with clear support needs, you'd effectively be fast-tracked through self-assessment to a process where you would then come up against an assessor who would, with you, work out what your effective proposal for a package looked like. So the self-assessment in many cases would bypass the early parts of that flow chart.

**MR JONES (SCIA):** I have read that chapter. I guess it ultimately comes down to who might the assessor be. Is there any idea as to where they're going to come from?

**MS SCOTT:** We have spoken to a range of organisations and asked them their views. We were thinking allied health professionals. We weren't suggesting that they would be GPs. They would need to be trained in a range of assessment tools. We've reached the view that it's unlikely that there will be one tool that could adequately reflect the diverse needs of a very, very widespread set of needs, so occupational therapists, physiotherapists. There might need to be multidisciplinary teams in the sense that paediatric specialists in allied health may be better suited to dealing with children than to someone with another set of needs. That's what we've been talking about. We've spoken to a number of organisations about the availability of that workforce and how long it would take to train people. That's our view at the moment. You might have a dissenting view to that or you might find that sounds alright.

**MR JONES (SCIA):** No comment at this stage.

**MS SCOTT:** Okay.

**MR KILLEEN (SCIA):** I assume the referral process to an NDIS would be either there would be some sort of contact pool. Someone may not know that they're eligible for it. They might go to a GP and he might say, "We'll refer you on. Ring this number for a second assessment."

**MR WALSH:** What we're hoping for is a much more visible stream than that. I think we would anticipate that everyone knows about the NDIS. You pick up the phone, you ring up the local office and they say, "You've got that condition. We'll put you through to an assessment process." I think the notion of GPs as gatekeepers is not something that we're proposing.

**MR KILLEEN (SCIA):** No.

**MS SCOTT:** We envisage this will be as well known as Medicare by the time governments have got to the stage of agreeing it and working on the finer details of it. But in some ways that would overcome any number of gaps in the system because people know, "Wait a minute, there's a service that exists." When they get to that service it might say, "Actually, what you're wanting to talk about is the Department of Public Housing," and might be providing referral services to people, or, "Did you realise there's a support group in your neighbourhood. Let me get the contact details for you," or, "Would you like me to make an appointment?" and so on. For some people it's that referral service. We would be pretty keen for the government to ensure that people knew the services out there and so on.

In terms of the initial call for action and public information campaign, I envisage organisations like your own would actually provide a very effective means to get messages out, what it was about, setting expectations and - - -

**MR BRICE (SCIA):** I think the better way that will happen - although I know you don't advise it in the report - is we certainly believe that there should in fact be some sort of levy to pay for this thing. That would, in a way, give the public some ownership of this scheme. You talk about the public knows all about Medicare and all, and I think if they were putting in a small levy each week knowing that it's going to cover all their future costs if they have a disability, or in their family, I think that's going to give them some ownership and they will certainly have more interest in the whole thing. If the government doesn't talk much about it beforehand to the public, the public will basically sit back and not worry about it. Do you know what I mean? We believe there should be a levy.

The only other thing I wanted to say was that in relation to court cases and common law cases, we believe that common law should still be allowed for loss of income and pain and suffering. We strongly believe that.

**MS SCOTT:** Okay.

**MR WALSH:** That's consistent with what we've proposed in the report..

**MS SCOTT:** All right. Thank you very much for coming along today.

**MR KILLEEN (SCIA):** Good luck with the rest of the hearing. We look forward to seeing the report and the recommendations.

**MS SCOTT:** Thank you.

**MS SCOTT:** I now invite the Australian Lawyers Alliance to come forward please and make their presentation. While they're coming forward we've been asked by one or two participants if they could speak after the lawyers and we've had two responses to that and both will speak for approximately five minutes. We have two people that want to do that. Can I check there's no other person that wants to do that now. Thank you.

Welcome to our hearings, and thank you for coming along. We've allocated 30 minutes for your presentation but could you please allow us a bit of time - John and I - to ask questions. Would you like to identify yourself for the record and then commence, please.

**MS GUMBERT (ALA):** Thanks for having us here. My name Jnana Gumbert. I'm the New South Wales branch president of the Australian Lawyers Alliance.

**MR ROYLE (ALA):** My name is Richard Royle. I'm a committee member of the Australian Lawyers Alliance and a former branch president.

**MR STONE (ALA):** I'm Andrew Stone. I'm the incoming New South Wales director for the Australian Lawyers Alliance.

**MS GUMBERT (ALA):** We would be happy to have this more as a discussion rather than us making a presentation. I'll perhaps just outline some of our main points to get started. The ALA supports the introduction of a national disability insurance scheme. We think it's necessary and we think it's desirable. As lawyers acting primarily for people who have been injured and have sustained a number of catastrophic injuries, we can see that there is a significant need out there for people, particularly in cases where they may not recover full compensation because of liability issues in their case. From that perspective we think it's certainly something we should all be embracing.

We think it's important that people retain common law rights, certainly at least in relation to those heads of damage that won't be covered by a national disability insurance scheme. Our primary position is that there should be a general opt-out entitlement for people who do wish to claim all of their damages under existing common law rights. There are some people who I think would have a preference to do that and to have autonomy over their future needs, but certainly at least the items that aren't covered should be retained for everyone.

Given you were speaking - I think that outlines the other main points that we wanted to make. They're fairly much all in line with what I've already said. We believe that the common law is a valuable thing to maintain. We think it does create a deterrent effect which makes society generally safer and that if you eliminate common law rights altogether - which I don't think is proposed - it would be a risky thing to do and would result in a generally less safe society, not to mention the fact that the costing of the scheme would be far more significant without any of those core law acts.

**MS SCOTT:** Thank you.

**MR ROYLE (ALA):** We're happy to take questions now, if you like.

**MR WALSH:** The only point of disagreement I think we have, compared to our recommendations and what you're suggesting, is the opt-out option for the head of damage of future care and support. So I'd like to talk a little bit about how that would work and how you would manage some of the risks involved in that that are issues with common law, in particular, I guess, what happens when the lump sum is extinguished before - - -

**MS GUMBERT (ALA):** I think the main problem for people who currently have common law rights and receive a lump sum payment is that the existing statutory schemes we have impose a discount rate that is too high which means that inevitably the lump sum is too low. One of the things that the ALA has been advocating for some time is for the discount rate to be brought down to a level that would mean that the money wouldn't run out. I think if that could be done then the concern about money running out too soon would be to a large extent eliminated.

**MR WALSH:** Can I just interrupt you for a second.

**MS GUMBERT (ALA):** Yes.

**MR WALSH:** It would be eliminated on average perhaps if the discount rate came down to, say, zero per cent as was recommended in Barrel back in 1980. But that's assuming that everyone lives to their exact life expectancy and everyone receives the exact investment return that's in the legislation. There will be many people who fall short and go over that, so it won't fix all the problems.

**MR ROYLE (ALA):** There's always the risk. We understand that. I had a bit of practice in the United Kingdom and I'm familiar with the system because I do go over there and do that, and the way the system works, both in relation to disability. I have a father who is disabled and works the disability system through the county council, as it works there, which seems to actually - over the last couple of years I've been - think what a remarkable system of how it works, and indeed many of the items that you were recommending here I notice actually mirrors the way the United Kingdom system works, and it seems to work - just talking from the coalface of my father - well.

But going back to the question that's being dealt with here, they have about a 2 and half per cent discount factor in the United Kingdom, and of course I don't necessarily follow through all the long-term needs of people who are catastrophically injured who I represented who live in the UK, but it does appear from what I understand from my colleagues who work over there, and also some of the major firms that operate over there, there does not seem to have been that problem.  But I believe, or I understand, if the problem in the United Kingdom occurred that the money ran out, it's on a means tested basis so that after the money ran out the county council system, where the council looks after the care, would step in - and does step in.  I don't understand - although I must say I don't have a great deal of knowledge - that it creates an enormous, or much of any financial problems to the system.  There are other problems to the system, like all systems, but I don't understand that to be the case.

**MR WALSH:**   It does add a cost to the NDIS which would mean that our estimated cost would have to increase to make provision for that.

**MR ROYLE (ALA):**   I would imagine it would be very minimal.

**MR WALSH:**   Well, if you have information on what that would be.

**MR ROYLE (ALA):**   It's something I might be able to do and we would be happy, as the ALA, to send some information.

**MR WALSH:**   I'd also like you to talk about - I mean, I'm not an expert on the UK system but was it Lord Pearson - - -

**MR ROYLE (ALA):**   Yes.

**MR WALSH:**   - - - who conducted a review of the system some seven or eight years ago and came down with a recommendation of structured settlements, rather than lump sums in order to overcome this difficulty.  So if the system worked so well, why would he come down with that recommendation?

**MR ROYLE (ALA):**   Well, the system in England now is that the structured settlement system is in place.  It's available here under our system.  It's not availed very often.

**MR WALSH:**   I think in fact once in the history - in the last 10 years.

**MS SCOTT:**   I think we might have met the individual in recent days.

**MR ROYLE (ALA):**   But having said that - and it's uniquely for the care only in the United Kingdom - most of the catastrophic injured cases that go through the court system in the United Kingdom end up with a structured settlement. There were some decisions recently handed down dealing with whether or not the structured settlement costs will be index linked in accordance with CPI, and it was decided by the Court of Appeal that that would occur. I haven't got a statistic but I do know that the vast majority occurred.

I just completed a case last December - in fact it was one of Jnana's firm's cases - in which again it was accepted, it was an English resident who was injured in New South Wales and in that case it was expected that it would be a structured settlement, as would always be the case, and the only reason it wasn't is that the defendant in that case - it was the TAC of Victoria - was not an authorised insurer within the meaning of the UK system, and therefore it was unable and a lump sum resulted. But that is very rare. Nearly always in the United Kingdom for catastrophically-injured people it would be a structured settlement, on the care only.

**MR WALSH:** The quantum of the structured settlement would still be determined with the statutory discount rate?

**MR ROYLE (ALA):** Yes, that's correct.

**MR WALSH:** And would be negotiated as if it was a lump sum?

**MR ROYLE (ALA):** It would negotiated as if it's a lump sum. So therefore the cut-off point, a point at which it would run out, but - no, sorry, that's not right. I think in fact what happens is it's negotiated on a weekly basis index-linked.

**MR WALSH:** I'm not sure that's correct.

**MR ROYLE (ALA):** I may be incorrect about that.

**MR WALSH:** I think the lump sum is required for the life offices to provide the annuity, whether it's an indexed annuity or not.

**MR ROYLE (ALA):** I'll confirm that. You may be right about that.

**MR WALSH:** I just have one more question on this. I'm going back to the Ipp Review of 2001, or whatever it was, tort law reform. What came out of that pretty much was that most of the states that didn't already have a 5 per cent discount rate increased their discount rate to 5 per cent in respect of most civil liability and health care liability legislation. So what you're going to ask them now is - for all of them, in respect of their motor accidents, civil liability, workers comp where it applies, and health care liability - to reverse the Ipp decision and take their discount rate down to 1 per cent or 2 per cent. How feasible do you think that is to do?

**MR STONE:** I think it's entirely unfeasible. Can I just clarify this. It recommended 3 per cent. The Ipp recommendation wasn't for the 5 per cent that everybody has, and, to be very blunt about it, the 5 per cent discount rate is a subsidy by the injured of insurance premiums, and it's subsidy through their future economic loss, it's a subsidy through their future care, both being not properly or adequately compensated.

You have the agenda of righting a particular set of wrongs through the set of reforms you're seeking. We have a righting of a different wrong, and the two overlap. If you ask us to be frank about the prospects that government will choose to take the politically unpopular choice of putting up premiums in order to provide adequate compensation for those who are injured, it's a difficult road. You'll probably know just how difficult it is when you start advocating putting the prices of things up in order to provide adequate care for the disabled. We have similar difficulties.

We like to see people given choices and to have the liberty, and I think that perhaps the important acknowledgment to make - and I've said this about lifetime care in discussions that you and I have had before - is that you're introducing a social welfare safety net, and it's one of which we are all in favour. But it has to be recognised that the social welfare safety net does come at the price of what I suspect is a relatively small number who would opt out and do better without that safety net, in the compensable field. I think it's just part of acknowledging in the process that there are those for whom this will be a drag back to the pack, because they could take their lump sum, invest it sensibly themselves and do clever and creative things with it.

On the other hand, I think they are a handful. When you're talking about traumatic brain injury, they're not going to get that choice. When you're talking probably about the most severe spinal injury, quadriplegic, given the escalating costs of care, I don't see how any competent lawyer with economic advice could advise their client to take the lump sum over the safety net. You're probably talking about a relatively small subset who would actually choose to opt out, if properly advised. What you do with those who are not properly advised is another problematic aspect.

I think what we're after is just an acknowledgment that, in the process of introducing a national disability scheme, for some who could otherwise take lump sums and move forward with their lives it will not work as well for them as the lump sum does. One of the things that has been talked about in New South Wales, and I'm not sure how far they have got with it, is trying to put people who can do that on annual budgets in order to create freedom and individual choice, and perhaps the halfway mark between our two positions is to make sure that there is the flexibility within a national scheme where those who otherwise could have made more get the opportunity to do so, rather than the government insurance company or the government welfare scheme and the dependent upon it style relationship.

**MR WALSH:** Andrew, I agree with you, and I think that sort of individual annual budget is something that we are certainly envisaging in the scheme. So that may be the way to go. The other issue around what you're suggesting, in terms of asking states to reduce the discount rates, is that we're also asking them to extend to those who don't have it their current coverage to no-fault, so there's a double-whammy effect - although that's going to be difficult politically.

I think the representation is good representation, like any service provision. In some cases the lump sum entitlement overwhelms the recovery process. I know you guys are recommending that there's effectively an immediate entitlement to care and support and there would be subrogation or recovery if the lump sum overtook that. Notwithstanding that, there will be cases where the vision of the lump sum interferes. Have you thought about that at all?

**MS GUMBERT (ALA):** Can I just present the alternate side to that, which is that I have clients who are currently members of the Lifetime Care and Support Scheme and I think it's a great thing that they're part of that scheme, because otherwise they would probably not be getting anything at the moment, due to liability issues. They're reporting that they wish they could just have this over and move on, because the constant involvement with the scheme with having people making decisions for them, having to ask for treatment, having to ask for changes to care is impeding their ability to move on and to recover. So I think that it works both ways.

**MR STONE (ALA):** That's a discussion, again, I think you and I had before the Lifetime Care and Support Scheme came in, that you're creating what will eventually become one of New South Wales's biggest insurance companies. You're going to create the nation's biggest insurance company, with a very large number of dependent clients. Certainly the common experience we have is that why cases settle isn't because the insurer finally offers the right sum of money, it's, "Get me the hell out of here."

**MR ROYLE (ALA):** Another example is I had one case of a person who was profoundly brain-damaged, looked after by a wonderful family down in Victoria, the TAC is the insurer - similar, although not quite the same as our New South Wales no-fault scheme. There a decision was to be made as to whether to remain on the TAC scheme, which was available at that point, or to take the lump sum. Obviously it's a matter where we give some advice, but we left it entirely obviously for the family to make a decision, and they took some advice. They were quite clear that they wanted the lump sum, and the matter resolved only last week. The reason behind that, as I understand it - from the sister, Maria, who was to be the primary carer - is that there was constantly a need every time she needed something to fill in a form, to have it reviewed, and it seems to be a little bit of a problem with the current scheme here in New South Wales.

Another guy, who is a double amputee, is in the scheme. It has taken him three years to get prosthetic legs. He actually lives in England now, he gets it through the National Health Service. For instance, he needed a bed. Because he has no legs, his balance is out. They were told he had to provide a report, he had to get an OT to send it through to Sydney. He waited about four months, and then they came back and said, "No, that's not good enough. We have to have a rehab person." This is the New South Wales system. They spent more than the cost of the bed sending an expert up from Oxford to Liverpool UK in order to say he needed a bed.

**MR WALSH:** That was within the Lifetime Care and Support Scheme?

**MR ROYLE (ALA):** That's within the Lifetime Care and Support Scheme.

**MR WALSH:** Look, if you could give us a submission on that, that would be good.

**MR ROYLE (ALA):** I'm not trying to criticise it, because I think it's a good system, I reiterate - - -

**MR WALSH:** No, of course not.

**MR ROYLE (ALA):** But you have got to avoid all bureaucracy in the new system, that's all.

**MR WALSH:** It's this dichotomy, being if you try to create a free market, will it emerge in the way that you would like. The answer to that is probably no.

**MR ROYLE (ALA):** Yes.

**MR WALSH:** So you try and direct the market or create the service support that's required, and that's never going to be a perfect process.

**MR ROYLE (ALA):** No, I understand that.

**MR STONE (ALA):** To come back to the angle I think your original question was taking about health outcomes, I think there is a very different debate that could be had about early access to medical treatment and rehabilitation in soft tissue whiplash injury cases versus spinal injury; you know, they're very different in terms of people's participation in the process and what health outcomes can be achieved.

With spinal injury you're not looking at a health outcome, you're looking at a rehabilitation outcome, and I think there is a difference between the two. Certainly access to funding can make a difference to that. Within the current CTP scheme there's access to funding for some cases, although not all cases.  In the serious injury field I don't think you see skewed behaviour as a consequence of the desire to hold out for the lump sum.  I don't think you see malingering and refusing to go back to work just because there's a pot of money at the end of it.  I don't think that's a relevant consideration in the field that we're talking about.

**MS SCOTT:**   I have just got one quick question, and I'm happy for you to take it on notice, because I'm conscious of the time.  When you talk about people opting out from the arrangement, is there then a later chance to opt back in?  Not just because of the preclusion arrangements but because the court case or the settlement was not to their liking.  Is that your view, that people would opt back in?

**MR ROYLE (ALA):**   I think at the moment there's a possibly in the current New South Wales scheme - and John will correct me about this - there's a buy-in provision.

**MS SCOTT:**   Yes, that's right.  But I'm not talking about a buy-in, I'm talking about, say, if someone says, "Now I'm going to go off and get a settlement," and in the end the settlement is either completely inadequate or didn't reach the outcome they sought, would you see the people having the option to come back in?

**MS GUMBERT (ALA):**   I think that perhaps the best way for it to work would be that people are automatically in the scheme until such time as they have a successful settlement, at which time the scheme is refunded for the period they were within the scheme, and there could perhaps be some benchmark about whether or not at that stage they can still opt into the scheme or not, depending on the outcome.  That might be something we should take on notice to provide a better answer to you.

**MS SCOTT:**  That would be good.  Thank you very much.

**MS SCOTT:** I think we had better move on. We have got a couple of people who want to speak now. I know it looks like we would be going to lunch now, but we have had two people with express requests to speak. Robert, I think I'll take you first. The other person who wishes to speak is William. We will do you second. Thank you very much for coming along today. Good afternoon, Robert.

**DR ZOA MANGA (ST):** Good afternoon.

**MS SCOTT:** Could you identify yourself, for the purposes of the transcript, and indicate whether you're representing yourself or an organisation. As discussed, we'd like you to confine your comments to about five minutes, please. I'll tell you when five minutes is up.

**DR ZOA MANGA (ST):** My name is Dr Robert Zoa Manga. I'm here to speak on behalf of the support group that founded Spinal Talk. That is a support group for people affected by spinal cord injury and disease. At the same time I'd also like to just briefly start with talking about my own experience. That reflects in our discourse with regard to the question that people in the support group that we run face-to-face and we also have a teleconference that we run twice daily all across the state. So we have managed to speak to people that have been isolated for over 30 years in the community that have never spoken to any service provider since their initial injury.

The first part I want to discuss is with regard to the individualised funding that is part of the proposed scheme. We couldn't be happier to have choice, flexibility and independence, ability to choose who is going to provide service, care and support to you and your family. But it comes at a price, because I was one of the first one that was involved in the ADHC, the pilot direct funded project. I received the funding, put it in an account that is - you have to do quarterly report and submit your annual report; the ability to recruit your own carer, because money is your own, this power, the funding, unless you have access to those funding you don't really, really have power, you don't have a say.

Prior to being part of the project I used to receive services from Home Care. I remember on a few occasions where somebody would call, given they work full-time, and you want to rest a bit on Saturday or Sunday, but they will call and say that they have a carer in my area 6.00 in the morning, or the next one is late in the afternoon. So since I have been in the individualised funding it's different, because I pay the carers, and I can tell them that I would prefer to get up about 11.00 on Sunday, that part is perfect.

But one issue I have found, and that we have been discussing in a teleconference is with regard to insurance, because when you take the project a lot of people don't realise that also they can not just use responsibility but that they have also got all the risk associated with their own life, their own care. So the problem is that if during the exercise of delivering that service to me one of my carers gets injured, they're insured, I have WorkCover third party liability. However, if they drop me during the exercise of their services, I'm left in the cold.

I am not alone, because every single one I discuss this with that's part of this scheme faces the same issue. That's not to say that I will advocate to not go to individualised funding, but there's a lot of work to be done in terms of finding information and in particular that program of insurance that have to be addressed, because I tried to get around it by trying to purchase life insurance, I found a broker that's got insurance, I fill out all the paperwork and I was ready to pay the premium.

They came back to me and said that I will only pay half, and I was that happy. They said, "You're only paying half because you are not covered from injury because you have pre-existing injury." That was it. I tried a second insurer, a third insurer, the same question. In teleconference, people I spoke to have a similar issue. So will the scheme provide for that type of insurance cover? Because what people said is that they will be happy to use some of their money provide it to buy for insurance, but they just want somebody to provide that type of insurance.

**MS SCOTT:** All right, I think I have got that issue. Have you got that issue?

**MR WALSH:** I just want to be totally clear, Robert. So the insurance you're purchasing is first party; so it's against you being injured or dying?

**DR ZOA MANGA (ST):** Yes.

**MR WALSH:** Okay. So if you were to be dropped in the course of care and you became a quadriplegic, say, you would want insurance in respect of that risk. Is that right?

**DR ZOA MANGA (ST):** Not just becoming quadriplegic; breaking my knee, like it happened a couple of months ago.

**MS SCOTT:** I think I've got it.

**MR WALSH:** Okay.

MS SCOTT: Yes. Robert, I think you're being clear. I understand that you're basically saying your workers can come with WorkCover, or effectively you've got WorkCover for them, but the question is you can't obtain insurance at the moment under your individualised funding package for the chance or the risk that while they're looking after you, with some movement, say, out of bed or something, you know, the hoist breaks and you drop to the floor and then you've got a broken leg, that you can't cover for that.  That's the issue you're concerned about.

**DR ZOA MANGA (ST):**   Yes.

**MS SCOTT:**   All right.  We have got that.  Thank you for coming along today.

**MS SCOTT:** William, if you'd like to come forward now, please. Good afternoon.

**MR DAVIES:** Good afternoon.

**MS SCOTT:** If you'd like to identify yourself and whether you're representing yourself or an organisation. I will strictly keep to the five minutes, just as I did with Robert. Thank you.

**MR DAVIES (CR):** I'm William Davies. I work for the City of Ryde, and I'm representing council here, only on certain issues. But I would like to make a more general submission later, which will cover other areas that I'm not able to talk about today.

**MS SCOTT:** Thank you.

**MR DAVIES (CR):** So I'm William Davies, I'm Access and Equity Coordinator with the City of Ryde council. What I want to talk about is perhaps that, with the terms of reference of such a commission as you would have, there isn't really the opportunity to look at other things which would influence the lives of people with a disability, their carers and the people around them that councils are responsible for. So I would like to make a submission which perhaps would address some of those things, where there's a kind of idea that by providing good living conditions in a local government area people would have better lives, would need less services, or would receive services from mainstream providers. In my job I'm also supervising a home modification and maintenance service for two local government areas, Ryde and neighbouring Hunters Hill, and also a volunteer referral service. So those are directly related to providing good service for people with a disability as well as for people with aged care needs.

Councils in New South Wales have a new, integrated local government planning and reporting framework and it's being introduced; we're gradually getting to a better system, I think, of social planning and planning for social inclusion. There is that mechanism now where we need to report and under that we're being encouraged and audited in the way we perform in a different way. Previously we had stand-alone social plans, and they've existed in New South Wales since 1998. But now we have a more integrated community strategic plan, which is part of the whole council operation. Those are four-year plans and they're audited on a four-year basis. I think that provides an opportunity for people to consult with council, for us to do a better job of including people with a disability. I'd like to pause and let you ask me about what, perhaps, you could direct me in writing a submission to you; what would be useful?

**MS SCOTT:** Because our time is so limited: William, if you could provide some examples, in your written submission, of how initiatives undertaken by the two local governments you work with have made, you know, a material difference to accessibility, or to the quality of life of individuals. Maybe it's the economist in me, but I was very much taken by the point that, if governments plan and think about the needs of people with disabilities, then there can of course be savings, and the fact that we wouldn't need to have such expensive packages, or there wouldn't need to be some of the private costs associated with that. So if you could had some real-life examples - very real-life; you'll see in the report that we like using examples and sometimes have them in boxes - that would be very useful indeed.

**MR WALSH:** I'd support you to make a submission and, as Patricia said, give us some examples. I think there's great opportunity for councils to contribute.

**MS SCOTT:** Really, some of the services you're talking about sound very much like tier 1 and tier 2. I don't know how long it took you to put together your voluntary referral service, but that might be very salutary for us to think about that as well. Any experience that relates to those two levels of service would be very useful.

**MR WALSH:** I think also your home modifications program. As Patricia said, you are describing the beginnings of what we would envisage tier 2 looking like.

**MR DAVIES (CR):** Yes.

**MS SCOTT:** Thank you very much.

**MR DAVIES (CR):** Thank you.

**MS SCOTT:** I now draw to close our hearings in Sydney, and thank you very much for coming along; I know that some of you have been here each of the three days, so it's very encouraging to see that level of commitment and all those people who presented. We look forward to getting your submissions by 30 April. Thank you very much. We now adjourn and we'll be commencing our hearings in Adelaide on Monday.

AT 12.40 PM THE INQUIRY WAS ADJOURNED UNTIL
MONDAY, 18 APRIL 2011