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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

DRAFT REPORT ON DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT MELBOURNE ON TUESDAY, 5 APRIL 2011, AT 9.00 AM

Continued from 4/4/11 in Hobart

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MS SCOTT: Good morning, everyone. Thank you for attending today's public hearing. My name is Patricia Scott. I'm the presiding Commissioner for this public inquiry. I think I'll now pause because we're just getting more chairs in. As this is a public inquiry and we want to ensure as many people can know the views of interested people, this session is being recorded for a transcript that will be available on our web site, pc.gov.au.

If you are interested in the other days of hearing - and this is our second day of hearing; yesterday we were in Hobart, the second day of hearing following the release of our draft report - you can go to the web site and progressively transcripts will appear there. You can also visit the web site to see other submissions that are being made, and at any time up until 30 April you can make a submission yourself on other people's submissions or you can make a comment on what you've heard today.

This is a public hearing and it means we hear it; it's not a town hall meeting. If you are scheduled to speak then we'd invite you to come forward at the time that we've allotted to you. If you would like to make a brief comment at the end of the day, I'll invite anyone who's interested in making a brief comment at the end of the day to come forward - but it's not a town hall meeting. I'm not going to be inviting comment from the floor because we won't be able to record it and then people won't know what you've said, okay? So, out of fairness, please don't make comments from the floor. Is there anyone from the media here today? Are there any media representatives, anyone from the press? No? Okay, thank you.

You're not required to take an oath to present your testimony, but the Act does require that you're truthful in your remarks. John Walsh is the Associate Commissioner for this inquiry and he will be joining us by Skype. He's just been detained for a few minutes, so by the time we get through the introductions and just start on some of the opening comments John will be joining us. But not to worry, if it turns out he's missed just a few minutes of your testimony; he has the opportunity to read the transcript like everyone else. Because we have a large number of people who are presenting today it's very important that we stick to the timetable, so I'm going to be quite a dragon on that.

I now welcome Deaf Children Australia. For the record, please, would you identify yourselves. We have allotted 30 minutes for the time and both John and I are likely to ask you questions at some stage, so you might want to take that into account in terms of not leaving your most significant point to the last two minutes, because you might find you don't get that. So without further ado, I welcome Damian, Julie and Debra and ask you to identify yourself for the record and to make an opening statement, if you wish.

MR LACEY (DCA): I'm Damian Lacey. I'm the chief executive of Deaf Children

Australia, an organisation of 150 years of age - or of youth - and I've had some 35 years' experience in this sector.

DR HALL (DCA): I'm Dr Julie Hall. I'm the manager of advocacy and campaigns at Deaf Children Australia.

MS SWAN (DCA): I'm Debra Swan, a mentor/coordinator for Deaf Children Australia, and I have a lifetime experience of deafness.

MR LACEY (DCA): Commissioner, I just thank you for the opportunity to be here. We have the opportunity to put written submissions further to the Commission, so we won't labour a number of points; we'll do that in writing. The opportunity this morning is probably more to listen to Debra's experiences, both professionally in the sector and as a person who has had a lifetime of experience of deafness.

Just a few remarks. We do agree that this is a great opportunity that the Commission has put before us to address the inequity that is within the system that we all understand. That inequity impacts heavily on the quality of life and support that we, as service providers, are able to consider. For example, the program that Debra runs - our mentoring program - relies wholly and solely on fundraised money and philanthropic money rather than on the needs of the children or the young people who are being supported. It is very limited in what we can do. Consumer feedback to us says, "You're always stopping and starting things. You have great ideas" - which we do, then we run out of money and we have to close programs down.

Another example is in the area of education, where in some states in Australia - for example, Queensland Education has committed $30 million over a five-year period to address and, by the way, this was following Deaf Children Australia and parents taking action through to the Federal Court, and many judges actually were involved in that decision. But following that, Queensland Education committed $30 million to change their policy around communication support, including creating communities of language for deaf children in that state. Go to other states and they don't exist. You're then back on fundraised dollars or philanthropic dollars to provide the same quality or attempt to provide the same quality.

We will address the issues of hearing aid and inequity there, and I'd like to just make some closing remarks around workforce development and competition in the sector - but you may have some questions, so I would like to hand over to Debra and Julie now to present.

MS SCOTT: Thank you.

DR HALL (DCA): Thank you. I'd like to draw the Commission's attention to several issues that impact on deaf children and their families and deaf adults, and Debra will be providing some life experience examples to illustrate the issues and how they impact. Firstly, in relation to Australian Hearing Services, access to support from Australian Hearing Services currently ceases at 21 years of age.

That's frequently a significant transition time for young adults who are entering employment or furthering their tertiary studies, and the inability to afford the expensive hearing aid repairs and replacements is quite a barrier for young people seeking to progress their career aspirations. Of course for Australians who are older and are currently ineligible for Australian Hearing Services, the costs of repairs and replacements can also prove prohibitive.

We consider that the NDIS provides an opportunity to remove the current inequities surrounding the provision of Australian Hearing Services and enables access to these services for all Australians across the lifespan - and Debra's going to give us an example of the impact of the Employment Assistance Fund's eligibility criteria on family budgets and quality of life. Thanks, Debra.

MS SWAN (DCA): I'm a profoundly deaf person so I (indistinct) yesterday. One example is my hearing aid actually costs $10,000 to purchase because of the degree of hearing loss I've got. So without EAF support, personally I wouldn't be able to purchase that myself, because I would think about other quality of lives that I might use it for. EAF only cover what's used for work (indistinct) funding. If it's used outside of home or anything then they only do partial funding, which again will - individuals will have to decide if they want to spend that extra money to purchase the hearing aids or not. So it could be like an adult who had two children and if they want to spend $10,000 on a hearing aid or they spend $10,000 on their children or providing a second car for their family so they can get around with the quality of life outside. Without EAF support I wouldn't be able to purchase these hearing aids on my own.

MS SCOTT: Thank you.

DR HALL (DCA): Secondly, we'd like to speak to the proposal for self-directed funding. A model of funding akin to that in the UK with the provision of self-directed funds would empower individuals and families to make the choices that best met their particular needs and reduced the barriers faced by deaf people in accessing everyday services. For example, parents of a deaf child may use it to purchase Auslan tuition for their family or respite care or a deaf mentor to help support their child, students may purchase notetakers in educational settings, and others may purchase Auslan interpreting services to promote independent access to non-medical activities - and Debra has an example of the need for access to Auslan interpreters for non-medical needs for deaf people.

MS SWAN (DCA): If I want to just go to the bank, where would I get an interpreter from? Banks don't provide funding for interpreters. So that means there's no funding; therefore I will struggle to communicate with an official to understand the information they might be providing to me about bank fees or loan fees and things that a lot of deaf people will miss out on. That situation results in many deaf people not understanding what's going on with their money, and get misinformed about a lot of the fine points that happen with banks, but they also have great barriers in accessing services such as chemists, so if I want to go to a chemist and I might get the prescriptions or anything like that. I have not understanding, communication barriers. Travel agents and accountants and taxation - and organisations like that, where there's no funding put aside into accessing interpreters.

MR LACEY (DCA): Can I just mention there also the issue of assessing those communication needs are often very difficult to make. I mean, ostensibly Debra can be here and speak with you, and you can understand that, although I imagine those who are going to transcribe the tape may have some difficulty who are not here to see the facial expressions, so assumptions are made of the communication needs of deaf people. So Debra is now using sign language to receive information but is able to speak back. That creates a dilemma in how you assess the level of support that is needed. But also the issue of legislation that requires reasonable accommodation, we have to challenge the provisions that are not provided and made within the community in some surprising areas, where unreasonable hardship is used as a reason why we can't.

MS SCOTT: Damian, if you don't mind the interruption in your thought processes and in your presentation, you said it's the challenge to assess the needs of an individual. I accept that, but is there something in the proposal as we set it out in the draft report that particularly causes you concern in relation to assessment, because we were proposing to use allied health professionals trained in assessment tools for the task. You've got concerns about that, or you can point to something that's better or - I mean, the fact that it's a challenge, I accept that. But is it not able to meet most people's needs, or hopefully address all reasonable and necessary needs?

MR LACEY (DCA): The example I can draw on is under the employment program, where I know collectively the deaf employment service in Australia were provided some training for the assessors of workplace - you know, the needs of people who had hearing communication difficulties to assess what they needed in a workplace environment. If you can get access to that specialist knowledge, then a therapist or an assessor can do the job, but you can't make that assumption that it exists, especially when you're trying to roll out a national program where presumably there'll be assessors or Gateway providers all around the place. The level of knowledge, just because you're a speech pathologist, for example, would not necessarily equip you - or a physiotherapist - with the ability to assess. Now, I understand the Commission is looking at a variety of tools, and I think there's a sort of kitbag of tools. It would be good to look at what's in that kitbag, and how the training of those assessors is conducted and accommodated.

MS SCOTT: Is there a particular assessment tool that you favour as an organisation?

MR LACEY (DCA): I'd have to draw on my professional staff to answer that question, if that's - - -

MS SCOTT: We'd welcome getting the input on that particular issue.

MR LACEY (DCA): We can - thank you.

MS SCOTT: All right. Now, back to where you wanted to take us in the discussion.

DR HALL (DCA): Thank you. We also note the potential interface dilemmas of the proposed NDIS, particularly with health and education departments; for example, the provision of audiology services to the deaf is arguably comparable to providing a wheelchair to someone who is immobile. Both deafness and immobility can be viewed as disability barriers, rather than solely health matters. Both require aids to enable full community participation, so we encourage the Commission to consider a deaf package of communication support within the NDIS which includes hearing aids, access to live captioning, Auslan interpreter services and notetakers.

Another example highlights the interface in the area of education. While public educational settings generally are in a position to provide Auslan interpreting services, those smaller private providers are frequently unable to afford to do so, and this limits access to a range of vocational training, to enable deaf people to enter, for example, the beauty and hairdressing industries and other vocational areas that typically have training via the private providers.

We note further barriers to equity that geographic or socio-cultural - have concern about the inequity of access to services for families who are non-metropolitan, those who live in rural or remote areas, and of course particularly the many Indigenous communities across the country. While it's argued that the rollout of the National Broadband Network has the potential to enable better access, this will only be realised if adequate funds are made available to communities to obtain those technologies by videoconferencing. Another area that's an interface: who will pay for that to enable that?

Further, assessing what's needed to remove barriers may involve more than simply a medical diagnosis or a disability classification. Some population groups such as the culturally and linguistically diverse communities, refugee communities, Indigenous families, for example, often face compounding psycho-social issues which also need to be taken into consideration and addressed when making assessments to overcome barriers to access. The deaf community experiences barriers to accessing affordable culturally sensitive therapies, and Debra has an example for us.

INTERPRETER: At this point I'd like to sign, because there are some words which I'll have trouble pronouncing, so for ease of all the speakers - therapeutic services provided such as psychology services, psychiatry services, specialists in the deaf area for deaf people are expensive, they are prohibitive. Many deaf people cannot afford to purchase such services. This is an area that needs to be addressed. We need more affordable therapies than those that are provided by Medicare. Many of the therapists don't have specialist understanding and skills or knowledge of what's required for deaf people who are currently on the Medicare panel or list, and only practise in private clinics and settings which are extremely expensive.

MS SCOTT: I wonder if I could ask a question here. You introduced this topic, Julie, as the difficult interface between health and education, and Debra has then talked about the expense of therapies and so on. One of the challenges the Commission faces is drawing boundaries around the scheme, otherwise the scheme would be taking into account everything, and would be completely unaffordable, so I'm just starting to see in your discussion that you're starting to encroach, I think, on what I would describe as health items. I understand your interest in having live captioning. That's still relatively expensive. Now Debra is talking about some health items. Is it clear in your mind, or could you explain to me where you see the scheme ending and the health system starting, please?

DR HALL (DCA):   That is a tricky question. I think that it's difficult - I can see the dilemma that the Commission will have, and I can see that it could be said that almost any provision is a NDIS provision, and making those distinctions can be difficult. I think that the example that I spoke to you of the wheelchair and hearing aids is a reasonable one. I think that it's comparable that access to everyday community activity is a disability issue, a disability access issue, and I think it is fair to say that if a wheelchair is going to fall into that category, so should a hearing aid, for example.

MS SCOTT: I'm comfortable on the hearing aid inclusion, but I guess when Debra was talking about some of the - and I imagine some therapies can clearly be in the scheme as well, but which therapies? What therapies do you see genuinely as health treatments and what therapies do you see as more related to the scheme? That's where I would like some guidance from your organisation. You've got lived experience and experts, and we would welcome that.

MR LACEY (DCA): I think the example that Debra used where, through a loophole - by the way, that loophole for hearing aids through the employment scheme has now been closed because of cost blow-out, and unexpected. I think hearing aids used to cost a couple of thousand once. They don't any more.

MS SCOTT: Yes.

MR LACEY (DCA): And with a young family, having to make a decision between family support needs and hearing support needs which affect quality of life. Technically, however, those aids are only meant for the workplace. So you get this gateway. Cochlear implants, for example, would be seen to be a medical intervention and a provision and yet there are a whole lot of other assumptions. If there is a very expensive medical intervention like that that happens for a child, what is the roll-on effect for accommodation, say, in the area of a case management or an ongoing support service, information advocacy, which are often not there?

DCA is doing some long-term research to look at language development because what happens is, post the medical interventions, often there isn't the ongoing rehabilitation and support that is provided by the health system. It's just that the person is sent back out into the big bad world for the family to actually just get on with it. I think that is the interface issue that is the challenge, although I agree that clearly mental health services at a point are mental health services. There is also a need for ongoing support advocacy information that needs to be part of an ongoing disability support community based system.

MS SCOTT: If I could urge you and anyone else in the audience to give consideration to this dilemma that we face of what's in and what's out and, also, if you're suggesting that the Commission considers items beyond the list we've already provided, which I admit does use the word "aids" but doesn't define it, you might wish to give definition to it. We'd also welcome any figures you have on the cost of live captioning per hour and the cost of the therapies that you consider would be appropriate, or as many costs as you can indicate, and the sort of hours that you think that people would need. That would be welcome in terms of our estimation exercises and our deliberations. John, is there a question that you'd like to ask at this stage?

MR WALSH: Patricia, I don't want to take up too much time, but I'd like to understand the relative merits and the interconnections between, for example, a cochlear implant and the need for further Auslan and hearing aids and other supports.

MR LACEY (DCA): Perhaps I could address that. There is a belief out there that if you have a cochlear implant - and also now the trend for profoundly deaf children often is a double implant, with supposedly the medical studies indicating that the benefits are there. However, we still face a challenge in Australia. Children may enter school with age-appropriate spoken language but they do not maintain it. The longer-term studies indicate that secondary schooling kids are two years behind, at least, their hearing peers in language.

There is a prima facie case that says that cochlear implants - and this is a worry about early intervention. I've seen a number of statements from government about if we get onto early intervention. We are working at the moment on a Better Start program. There's a whole focus around if we get the best start in the under-school age, then we are going to ameliorate some of the - well, we will. We will. If children and families could get a good start and better access to communication information, they will have a better quality of life. However, it does not mean that ongoing services won't be required at critical points in their lives. For example, in the area of mentoring that Debra talks about, there is a big need for mentoring in terms of identity for young adults moving from the protective environment of school to university and work, as hard of hearing; those who have grown up as aural deaf young people, without a deaf identity as such, because they have been mainstream.

Australia has one of the highest incidence of mainstream and integration of deaf and hard of hearing kids in the world; about 86 per cent of children with hearing loss in Australia are in a school, on their own, in their own class, with other hearing children. The quality of support they get varies absolutely enormously from full-on individual support workers, access, notetakers, live captioning, through to nothing, or a monthly visit from a well-meaning teacher.

MS SWAN (DCA): I think my example is that, yes, hearing aids help me (indistinct) improve the sounds coming in. I can hear where the sound is coming from but I cannot understand speech, speaking really. So it gives me the sounds coming through one-to-one. When I'm one-to-one with someone, I generally don't have that much of problem except for if they have an accent or too much facial hair, but in a big group, that's when I struggle with understanding what's going on or where the sound is coming from. We have to focus on the person to know what's actually being talked about. But for someone who has never heard a particular word would not always understand what it actually means.

MS SCOTT: I understand. Thank you.

MR LACEY (DCA): Just another example of where the law changes - the issue of fire safety and fire alarms in your house; smoke detectors: it's law that you have to have them in your house, yes?

MS SCOTT: Yes.

MR LACEY (DCA): Various state governments have had a struggling response to that. For example, in Victoria, I think the Fire Services Commission, or someone, ended up having a few thousand dollars that were allocated, and so 200-odd deaf people could get access to support. The aim here was that the additional cost of having a hard-wired system that would work with strobing lights could be accessible.

At the moment, we're just putting in a reviewed submission to actually include families with children who are deaf. At the moment you have to be an adult in a family to get this additional support. If there's a child, you don't. So if mum and dad leave the 13-year-old deaf child in the house on their own, there is no visual alarm system within it. The cost of that additional interface there, is that something that should be part of this aids and provision of support, or is it a Fire Services, or is it a health issue? Whose responsibility? Which part of government picks it up? I think that's part of the unfunded issue of quality of life for people with disabilities; to live a quality of life which is acceptable and that we take for granted.

MS SCOTT: Thank you. I'm just conscious of time, so imagine you've only got five minutes left, please.

DR HALL (DCA): I just want to add briefly to Damian's comments about early intervention and language delay. We consider it's important that all hearing-impaired children have timely access to early intervention, regardless of their degree of hearing loss. The research shows that all these children are at risk of language delay, not simply the profoundly deaf. So the risk is that the assessments determine the need on the basis that the child's level of hearing loss might prevent full access to valuable preventative early intervention services. Of course, language delay can have lifelong implications for individuals. Notably, family Auslan tuition can help to support early language development and it's of concern that the Auslan tuition is not included among the therapies that families may purchase under the guidelines of the shortly-to-be implemented Better Start Early Intervention packages.

We think it's important that there are specific knowledge and information services to increase deafness awareness in the wider community and provide information services that are knowledgeable about deafness. Lack of deafness awareness can lead to inappropriate expectations, poor communication and social isolation, and I know that Debra has an example from a school setting.

MS SWAN (DCA): Deaf children who are placed in mainstream school near their homes quite often have limited access to communication with peers and opportunities to meet their social needs. Being in mainstream school - and I come from a mainstream school when I was growing up - is that it gets really, really tiring, when we are focusing on the teachers, lip-reading them. We have limited access barriers so we have to focus on them. So by the time lunchtime or recess time comes around, we are so tired that we just isolate ourselves even more from being with our peers in the classrooms, in the playground, at recess and lunchtime, so it becomes very tiring. At the end of the day it's like we don't want to socialise with our family, as well.

Staff in the general education system don't always have a full understanding of the needs of a deaf child and it will vary, depending on the degree of hearing loss they have Some of the examples and comments that I often hear that tells me they misunderstand the deaf child's needs, including "Don't speak to me" so that means they hear me. They understand what is expected of them. So a lot of people assume with technologies that are available, like hearing aids or FM systems in schools, and sound systems, and all that, is that they hear just like a normal person.

MS SCOTT: So you are pointing to - that there's still this misunderstanding on the part of teachers in mainstream schools about the extent to which the impairment is overcome by the aids around them?

MS SWAN (DCA): Yes.

MS SCOTT: I got that. Thank you.

MR LACEY (DCA): I'll just maybe wrap it up quickly. Just in general, workforce capacity: most deaf people have their needs met in the community - - -

MS SCOTT: Yes.

MR LACEY (DCA): - - - unlike other disabilities. I think in shaping a disability insurance scheme we have to be aware of that; that deaf people are not a major impost like some other physical needs that require 24-7 care, for example. Deaf people aren't like that. However, if we assume that the community absorbs and meets their needs, it's a wrong assumption: things like, for example, as Debra mentioned, the need for continuing advocacy and community education, so the funding of some base that continues to educate and support the community in creating better opportunity and more opportunity; whether it's recreational, whether it's cultural, whether it's captioning for cinemas. I mean, you'd be aware of some of the campaigns that have taken place at that sort of level in Australia that create enormous opportunities in terms of quality of life by just being clear about - having screen reading and captioning. Things like that can change lifestyle for people and I think that's a big one.

We can't assume also that the community can provide capable workers out there. So I think there's a whole issue about addressing - in our case, for example, Paul, an interpreter. We have a major scarcity of interpreters in Australia, of high-quality interpreters. We need to address the issue of where do we get the skills we need? Are the current therapy based styles adequate; for example, under the new Better Start program, language provision in Auslan? Teachers of the deaf are not accredited providers under that new program, which is a real challenge because they have been the traditional base of a lot of early intervention services. They're now not able to be provided unless they're in a multidisciplinary sort of environment in the new regime. Pricing - - -

MS SCOTT: Last point.

MR LACEY (DCA): Last point. We welcome opening up to competition. DCA is a provider of quality employment services in a number of environments where we have been able to provide a niche market quality and a viable business within a competitive framework. However, pricing needs to take into account the need for - I mean, at what price? Will it be at a lowest denominated price, or will it actually address the issue of capital and the need for ongoing quality provision and sustainability for this sector? Yes, the not-for-profit sector does need continuing support.

MS SCOTT: Maybe on that point, Damian, I can refer you to another report that the Commission worked on and which was for the not-for-profit sector.

MR LACEY (DCA): Yes.

MS SCOTT: One of the key recommendations there was that too many governments were requiring tenderers to price at a level under, effectively, the commercial price, including capital costs and including normal business practice, always assuming that they had to be done at a sort of charity cost. So we understand that point very well. So thank you very much.

MR LACEY (DCA): Thank you very much.

MS SCOTT: Thank you to all three of you for coming along today. Thanks, Paul.

MS SCOTT: We now welcome the National Ethnic Disability Alliance to come forward. Thank you very much. Good morning and thank you for attending and providing testimony today. Would you like to state your name and your organisation, please? You have 30 minutes.

MS KACZOREK (NEDA): Thank you. My name is Sibylle Kaczorek and I'm the executive officer of the National Ethnic Disability Alliance.

MS SCOTT: Thank you. Would you like to make an opening statement?

MS KACZOREK (NEDA): Yes, thank you. First of all, thank you for the opportunity to present to you today. Obviously the National Ethnic Disability Alliance will also make a written submission, so I'll be touching on issues that will be covered in the written submission also. The National Ethnic Disability Alliance is the national peak for people from a non-English-speaking background with a disability and their families and carers. We're funded through FaHCSIA and we've been in existence for around 15 years and we've got a consumer-run council. So that's our governing structure, I guess.

The points I want to touch on today I'll sort of list in seven different categories. I'll just run through them and then go through them in a bit more detail. The first one is eligibility for non-permanent residents - and I'd like to touch on that; then the issue of cultural-centred care and support; thirdly, on access to interpreters; fourthly, on access to culturally competent advocacy; fifth, a non-English-speaking background or culturally and linguistically diverse strategy; sixth, on data development for people from a non-English-speaking background; and, seventh, on the trial or the potential trial that the Productivity Commission is putting forward as one of the recommendations.

Just before I kick off that discussion, I wanted to point out a couple of statistics, and these statistics actually come from the Productivity Commission's Report on Government Services 2009. In that report the Productivity Commission found that people from a non-English-speaking background are substantially less likely to access disability support services. When it comes to disability accommodation support services, people from a non-English-speaking background are four times less likely to receive these services. When it comes to community support services, people from a non-English-speaking background are around 2.5 times less likely to receive these services; community access, around 2.5 times less likely; respite, around three times less likely; and employment services, around two times less likely.

I guess I'm starting off our discussion with those statistics in order to illustrate that there's a current inequity when it comes to access of services to people from a non-English-speaking background. I might just also point out that the National Ethnic Disability Alliance is using the term "non-English-speaking background" rather than "culturally and linguistically diverse background". We understand that the government is using the CALD term in preference. However, I'm just used to that language so I'm going to stick with it.

MS SCOTT: That's fine, thank you.

MS KACZOREK (NEDA): Okay. So when it comes to eligibility of non-residents, I guess NEDA - the National Ethnic Disability Alliance - questions the blanket exclusion of residents that the Productivity Commission is putting forward at this stage. We're suggesting that children, if they're not eligible to early intervention services, potentially later on when they may become permanent residents - that will substantially develop into a substantially higher expenditure later in life and, obviously, lost opportunities. So we're putting forward that children should be included regardless of whether they have residency status or not.

We also point out that asylum seekers currently, under the Asylum Seeker Assistance Scheme, receive health and welfare services and also have temporary eligibility for Medicare. So we think there needs to be some consistency when it comes to eligibility for asylum seekers there.

MS SCOTT: Can I just ask a question there, Sibylle?

MS KACZOREK (NEDA): Sure.

MS SCOTT: Could you just go through in a little bit more detail about the asylum seeker status? What particular status do they have, because sometimes that phrase "asylum seeker" is applied to everyone who's moving through the process? Do they have to have passed a certain point in the process to be able to receive this assistance?

MS KACZOREK (NEDA): I actually can't answer that question on the spot, but - - -

MS SCOTT: Okay, that's fine. You might take it on notice then.

MS KACZOREK (NEDA): Yes. What we're putting forward, though, is definitely that asylum seekers that are in detention centres at the moment, in immigration detention centres, should be included in the scheme.

MS SCOTT: Okay, I'll just explore that a little bit further. Some of the therapies and some of the aids and appliances that we've defined here, some may fit immediately into the category, as you've suggested, of early intervention; some may fit into the category that they're essential for the next stage of life or for current living; and others, I think, are about that longer-term investment, for example, having someone trained - say public transport - if they've got intellectual disabilities, so that they can then move around in society. The provision of health services for someone in detention probably goes to basic provision of services. It probably doesn't go to a higher level of services. I'd just be interested to find out a bit more about the treatment of asylum seekers and the principles you think we should apply and how you'd relate those principles back to other services that relate to asylum seekers. Have I been clear?

MS KACZOREK (NEDA):   Yes. I think we haven't explored that at this point, and that's certainly something that we'll take back in order to look into that in a little bit more detail, but when it comes to people that are currently in detention centres, for instance, obviously they would not require assistance for independent transport access. However, they may require aids and equipment in order to independently move around in the detention centre, so it obviously depends on what kind of circumstances they are in, in terms of their freedom of liberty at the moment.

MS SCOTT: Yes, but I'm sure if I go down through that list, I can probably find other items that a person could receive in a detention centre that they may in fact not receive because of their current status in terms of uncertainty about whether they're staying in Australia or not, so I'd just be interested if you could go through that list and just see whether you think everything should be applicable, or whether you think there needs to be some distinction between them.

MS KACZOREK (NEDA):   Sure. I mean, we can go through that; we can hand that it in.

MS SCOTT: Thank you very much.

MS KACZOREK (NEDA):   The other group of people I want to list are the temporary business migrants, 457 visas. We believe that at the moment, 457 visas can waive for health assessment, and so therefore there are currently residents in Australia who have a disability of some form. So we are suggesting that to exclude people who are on the 457 visa would potentially be detrimental to Australia in terms of addressing skills shortages, et cetera. Also we're making a reference in our submission that one of the figures we've come across is that that particular group of visa holders makes a substantial contribution financially to the economy, and that was 12 to 13 million dollars in 2008 and 2009, and therefore we're suggesting that that expenditure is actually financially sound. We've also done a bit of, I guess, looking into the numbers, and we're suggesting that there will be 16 people with disability for a thousand 457 visa holders. Obviously we're going into a bit more detail in that in the submission.

The other group we want to suggest to the Productivity Commission is student visas. Again, there's a health waiver possible at the moment under the current system, and again we're suggesting that there's a strong social and economic contribution made to students coming to Australia. It's obviously one of the key national industries in Australia, and including eligibility for student visas would be recommended.

The last point on eligibility that we wanted to raise are the international social security reciprocal agreements, and I guess we're just making a recommendation that those agreements should be extended, and that obviously would be also in the interests of Australian residents with disability who may require coverage overseas. So, as a minimum, what we're suggesting is that the National Disability Insurance Scheme, whatever it may look like in the end, should be accessible to those groups that are already identified through other schemes at the moment.

The second point I want to touch on is the culture-centred care and support. Individualised funding agreements will not be effective for people from a non-English-speaking background with disability, unless they're designed to respond to diverse needs. The need for this is - I think I've just established before in my opening statement in terms of the lower rate of uptake for services. So one of the things we want to point out is the capacity to employ a family member as a formal carer, and we've researched some evidence from the UK which suggests that establishing a transparent and understandable option by which family members can be employed as carers will be necessary in order to provide culturally competent services for some people from minority ethnic groups.

A recent New Zealand High Court decision suggests that a system that prevents a family member from being paid to care and support workers for a person with a disability is potentially discriminating to both the family member and the person with disability. We understand that the Productivity Commission has looked into that, and that you've identified some risks of dependency. The New Zealand High Court decision is quite instructive on that, and it found that there was some risk of dependency in payments made to family members providing care and support, but it did not believe that this was a reason to prevent family members from receiving payments, provided appropriate checks and balances were in place.

Importantly, the High Court observed that there was strong evidence to suggest that utilisation of family members as paid carers and support workers for people with disability would lead to different outcomes in terms of quality of care. Above all, the New Zealand High Court decision found that a policy of excluding family members from being able to be paid to provide care and support was discriminatory. So at the same time, while we're suggesting that the Productivity Commission should look into that and be supportive of that recommendation to allow family members to be paid, we're also suggesting that that has to happen simultaneously with the resourcing of support to establish and maintain specialist multicultural brokerage providers and multicultural service providers.

The proposed long-term care and support scheme, in combination with an individualised funding model, will create an unprecedented application of market principles to disability services. It is possible that many people with disability will benefit from the new arrangement through increased choice and, depending on the model chosen, value for money and being able to maximise allocated care and support budgets. However, the experience is likely to be different for other consumers with specialised needs, where the market is unlikely to deliver choice, and in some cases will be unable to deliver as needed.

For example, African people with disability may not be able to have a choice of providers if they want a culturally competent service. There may only be one service available, while for some language groups there will be no same language service available at all. There are likely to be differences between the experiences of urban and regional consumers; for example, Chinese speakers in Sydney may be able to resource a service that may not be available in a country area.

Resourcing for individualised service through a long-term care and support scheme would be oriented to address market failures to particular groups of people with disability. In the case of services of people from a non-English-speaking background with disability, a commitment to establish and resource multicultural brokerage services and multicultural service providers will address this market failure by guaranteeing a level of choice to people from diverse backgrounds.

MS SCOTT: Sibylle, can I just check: so while you welcome the idea of individual packages for people and people being able to make choice, you also are I think advocating block funding for specialist long-term brokers for people with cultural and linguistic diversity. Is that right?

MS KACZOREK (NEDA): That's correct, yes.

MS SCOTT: Okay, I've got that. John, is there any question you'd like to ask Sibylle at this stage?

MR WALSH: No. No, I'm okay, thank you, Sibylle.

MS SCOTT: All right. Please proceed.

MS KACZOREK (NEDA): The next point in terms of culturally responsive service delivery is the availability of translated, easy to understand and accessible information. Translated, easy to understand information is one effective way to reach people from a non-English-speaking background with disability and their families. In New South Wales, for instance, that's one example we are citing, there is a New South Wales health policy directive, and that provides a framework for the use of translations to improve non-English-speaking access to health services, and that's including ensuring adequate supply of relevant multilingual publications that should be prominent on display at public contact points, ensuring all translated material is available free of charge, specifying that all general material available to English-speaking patients must be available in translation into community languages.

The next point is the cultural competence frameworks that need to inform promotion, intake and assessment procedures for all providers, and flexibility in-built into standards and guidelines. Cultural competence approaches have been utilised in the US, UK and in Australia to improve the effectiveness of human services for people from diverse culturally and linguistic backgrounds. Cultural competence frameworks acknowledge that organisational culture contributes to poor responsiveness and seek to make progressive change across all aspects of the organisation in order to enable organisations to meet the needs of people from different cultural backgrounds. So basically that's the various points under culturally responsive services.

MS SCOTT: Yes. Thank you.

MS KACZOREK (NEDA): The third point is access to interpreters. At present, there is evidence of inconsistency in the provision of interpreting services to people with low English proficiency who are navigating disability services. While the Australian government offers telephone and on-site interpreting through the national telephone interpreting service, they are not provided to non-government organisations that receive funding for delivering their services. This means in a practical sense there is a disincentive for many organisations to offer interpreting services, particularly as noted in the review of services to migrants where there is an inadequate budget provision by service agencies, reluctance to pay for translating and interpreting services, and/or a lack of experience or training in using these services.

Failure to address interpreter needs in costing for the proposed insurance scheme could mean the continuation of existing poor practice, or worse: if an individualised funding system is created, individuals may be required to meet the costs of interpreting services from their own packages and that's certainly a danger that we are clearly identifying and we believe needs to be mitigated against.

MS SCOTT: So this is the difference between provision for the individual and mainstream provision. Could you give an example where the fact that organisations' funding doesn't include cost of translation impacts on individuals in the communities that you are concerned about?

MS KACZOREK (NEDA): The best example that I can give is the lack of utilisation of people from non-English-speaking backgrounds to the services. So, unless there is a proactive approach to making extra interpreters available, people simply won't use the services, and that is reflected in the statistics. If the Productivity Commission was interested, we can provide some case examples of where that happened and what kind of impact that may have had on an individual person.

MS SCOTT: Yes, that would be useful. Thank you.

MS KACZOREK (NEDA): That will be fine.

MS SCOTT: I take the point you're making, but I'd like to be able to illustrate what that actually means to a person.

MS KACZOREK (NEDA): Yes, sure.

MR WALSH: I have a question on this one and there's probably not an easy answer. But this strikes me as a little bit like the border issues between disability and health. The National Disability Insurance Scheme is designed to provide funding to support the needs of people with a disability. The extent to which those support needs extend into translation services, I think, is an issue we need to think about. There are other government agencies - I'm not very familiar with them - that are responsible for issues of non-English-speaking background, so I think this is another issue of border responsibility that we might need to think about.

MS SCOTT: Yes. I think Sibylle's point, if I understand it correctly - just see if I've got it: your concern is that if the assessment process involves seeing, say, an older member of a community who feels more comfortable in their original language than in English - - -

MS KACZOREK (NEDA): It could be a younger member as well.

MS SCOTT: It could be, yes, but just for my example we're going to pretend the person is an older Australian and that if the package included interpreter services, then that potentially reduces funding for other services the person might need, whereas you consider availability of interpreters to be part of what should be existing in mainstream programs generally.

MS KACZOREK (NEDA): Absolutely.

MS SCOTT: All right. I'm sure we've got that, haven't we, John?

MR WALSH:. Yes. That's a reasonable position, I think.

MS SCOTT: Thank you.

MS KACZOREK (NEDA): Basically what we're putting forward as well is that there is actually precedent to allow for that, and that is with the current availability of the national telephone interpreting services. So some of the examples are that at present private medical practitioners providing Medicare rebated services and their reception staff can access the free telephone interpreting services, so we're not suggesting anything that is not already in line with current practices in Australia in other service delivery arrangements. We're just essentially saying that that should apply equally.

MS SCOTT: Yes. That's a good example, the Medicare one.

MS KACZOREK (NEDA): We will provide to the Productivity Commission in our written submission as well - actually we've done a bit of costing on that and what that would mean, and our costing comes up to $51 million per annum, and that also includes Auslan interpreting and it also includes interpreting for Aboriginal and Torres Strait Islander people, so we'll be submitting that also.

MS SCOTT: Thank you.

MS KACZOREK (NEDA): The next point I want to touch on is access to culturally competent advocacy. The existing proposals for the long-term care and support scheme do not explore funding for advocacy, including systemic advocacy. Given the role of individual and systemic advocacy in enabling people with disability to navigate mainstream and specialist disability services and access rights, there's a strong case for any new scheme to also meet the advocacy needs of consumers as an integrated facet of long-term care and support. We're making that point very clearly as an independent organisation. There is some talk in the Productivity Commission report on mixing that in maybe with one of the disability service organisations, but we are saying that advocacy needs to be separate.

Governments currently fund multicultural advocacy providers to provide specialist individual and systemic advocacy for people from non-English-speaking backgrounds with disability. Multicultural advocacy providers play an important role in providing culturally appropriate advocacy to people from non-English-speaking backgrounds with disability, assisting mainstream advocacy providers to become culturally competent, and working with governments and service providers to improve their responsiveness to people from non-English-speaking backgrounds with disability.

Existing funding for multicultural advocacy providers is inconsistent. Specialist multicultural advocacy providers exist in different states and territory jurisdictions, although funding for these providers is often limited and some states are lacking any multicultural advocacy at the moment. These are ACT, Northern Territory, Tasmania and Queensland. In lieu of consistent funding rationale and a modest commitment to funding advocacy services in those states, we would propose that they need to be accessible across all states and territories, and we've done a very modest costing on that again and that would be $7500 per annum. Then the next point I'd like to touch on is a specific strategy as part of the long-term care and support scheme.

MS SCOTT: Sibylle, you've got about five minutes.

MS KACZOREK (NEDA): Okay.

MS SCOTT: And I've got one question, I think.

MS KACZOREK (NEDA): You may be aware that the Survey of Disability, Ageing and Carers released data on 1 March, very recently - a month ago - noting an average disability rate of 18.5 per cent in Australia. However, the average age in that data collection for people born in Greece is 45.7 per cent, people born in Italy is 45.5 per cent, people born in the Netherlands is 34.7 per cent and people born in Germany is 32.9 per cent. This higher rate of disability and the previous mentioned underutilisation of disability services for people from non-English-speaking backgrounds demands a dedicated strategy for people from non-English-speaking backgrounds as part of the NDIS. Essentially, what we're putting forward is that that strategy should mirror the strategy currently identified for Aboriginal and Torres Strait Islander people, given the higher rate and the underutilisation.

MS SCOTT: That could be reflecting the phase of migration, waves of migration of people coming through. You could easily have an age demographic occurring with those three groups that you identified.

MS KACZOREK (NEDA): That's correct. However, if I have the time, I'm going to touch on data as well. I know that the Productivity Commission in its first draft report took on some of the comments NEDA made about data, but there is a lack of data on non-English-speaking background because it's primarily on country of birth rather than second and subsequent generations. However, in our own data analysis that we've done over the years, we've actually found an earlier onset of disability for people from non-English-speaking backgrounds. So I take your points on board in terms of the age demographic, but there is also additional evidence to suggest that there is an earlier onset of disability for people from non-English-speaking backgrounds. We've identified from 45 years onwards.

I might actually go into the data development. So currently there is a failing of national data collection on second and subsequent generations of people from a non-English-speaking background with a disability. That data does not exist. The census data is very good on ethnicity, including second and subsequent generation. The SDAC - the Survey of Disability, Ageing and Carers - was unable to do that. Given the lack of data on this cohort of people, the consequences are obvious, if there's no reporting, no analysis on life outcomes and no development of service planning and delivery to meet the needs of people from a non-English-speaking background with disability.

There has been an improvement in the SDAC development, and NEDA has certainly been lobbying to the best of our abilities. The most recent change was from 2003 to 2009, because of course the survey is only every six years. The 2009 data has now also included an element on language spoken. However, those figures haven't been released yet, so we can't actually comment on those at this point.

I've finished on my last note in terms of the trial or early rollout of the scheme that is being proposed by the Productivity Commission. We would certainly strongly motivate for an area to be chosen with a significant population of people from a non-English-speaking background in order to allow some research and analysis of what kinds of strategies, what kinds of measures are taken, what kind of uptake of the scheme we can identify for people from a non-English-speaking background before the major rollout happens.

MS SCOTT: Thank you very much. John, do you have any further questions for Sibylle?

MR WALSH: No. That was very comprehensive. You're going to provide a written submission as well, Sibylle?

MS KACZOREK (NEDA): Yes, as well.

MS SCOTT: I've got one quick question. I'm going to be disciplined. We do make a recommendation in the draft report about a trial of volunteers who would like to have family members as paid carers, under very strict trial conditions. I just wanted to check: were you aware of that recommendation? If you were aware of it, are you suggesting to John and I that we go further, or are you comfortable with that recommendation and think that's the way to proceed in terms of your reference to the New Zealand experience of use of family members as paid carers? I just want to clarify.

MS KACZOREK (NEDA): Yes, our recommendation is that it is available from Sydney.

MS SCOTT: So you don't want a trial. You want to go straight to the institution of it?

MS KACZOREK (NEDA): We think that the international evidence that is available at the moment is sufficient to warrant it, yes.

MS SCOTT: Thank you. Thanks for the brief answer as well.

MS SCOTT: Our next presenter is Philip Gluyas. Welcome, Philip, to the table.

MR GLUYAS: Thank you.

MS SCOTT: Could you just state your name for the record. I understand you are representing yourself?

MR GLUYAS: Yes, as an individual. That's right.

MS SCOTT: Philip, you've got 20 minutes, and I'll keep you to that so we can ensure that the other speakers have their time as well.

MR GLUYAS: Yes. I'll do my best, because I've undergone a couple of changes in my presentation as a direct result of my meeting with the CEO of Autism Victoria, Murray Dawson-Smith, who I understand is making a presentation here tomorrow. I spoke to him on Saturday morning during the Autism Awareness Walk which we had down at St Kilda, which was highly successful, if I may say so.

MS SCOTT: So, Philip, allow some time for questions.

MR GLUYAS: Yes.

MS SCOTT: And your time starts now.

MR GLUYAS: I just wanted to make this presentation. First of all, being on the autistic spectrum myself, being diagnosed with Asperger's syndrome - which, under the DSM-V which will be introduced in 2013 will all be known as "autism"; the entire autistic spectrum - I've got some concerns about the draft report, in particular the fact that, from the way I'm reading it, autism is not being covered for adequately under the recommendations of the National Disability Insurance Scheme.

I want to point out that I do give a tick for the general concept of the NDIS: it is a good idea. When I was making inquiries during the Victorian state election of policies and so forth, I found it was an Australian Greens' policy, originally, which the Labor Party have now taken up. So I do give the approval.

Because I've got the 20-minute time limit, and to give you time for questions, I'll just go straight to some of the points I've got here. First of all, in reference to table 1, the outcome and problems of the present system, I want to make some comments on the last section, the "poor evidence base" for which it's proposed that the "research function and evidence-based practice" - a very generalised and ambiguous term.

The reason why I wanted to bring that to the attention of the Commission is because I have some very severe concerns about a lot of the poor information that has been spread about autism, in particular on the Internet. We, the autistic community, have been subjected to a lot of snake oil style treatments - in most recent times coming out of the United States - based on the idea that vaccines cause autism. That's starting to come into Australia through the Australian Vaccination Network ….

Vaccine causation, whether it be by content of the vaccine itself or - I know this doesn't apply to Australia any more, but through thiomersal as a preservative in the vaccine - ie, mercury, or ethylmercury as it's known specifically - that being a causation of autism - ie, autism equals mercury poisoning, which is not the case at all - I believe this comes from the system not keeping up with parents who are having to cope with not just people on the spectrum at my level but also those who are parents of low-functioning autistics. They feel left out by certain state systems. Victoria is not too bad. I've heard some nasty things about Queensland, and I've heard some good things about Western Australia, just to show that it varies from state to state.

All this lack of information or poor information, poor evidence base, as I said, is leading parents and carers of autistic children to go onto the Internet and start believing this nonsense and, as a direct result of that, actually doing some harm to children on the autistic spectrum.

Now, I hate to speak negatively of an unfortunate accident, but I assume you are aware of the train accident that happened down in Geelong just last week, involving a six-year-old autistic boy who was hit by a train at Corio.

MS SCOTT: Yes.

MR GLUYAS: I look upon that - notwithstanding, of course, the fact that - - -

MS SCOTT: Sorry to interrupt, but because this is actually a public transcript and will go up on our web site, can I just make - - -

MR GLUYAS: I'll choose my words, carefully, yes.

MS SCOTT: An element of caution here, because we wouldn't want to see any problems in terms of public defamation.

MR GLUYAS: Yes.

MS SCOTT: You might take that into account.

MR GLUYAS: Yes.

MS SCOTT: I know you're talking here, and in this audience, but there's a bigger audience out there and you need to take into account any risks in terms of legal responsibility.

MR GLUYAS: Yes, I have deference to that, because it's an example of a mentality that's coming out, again from the United States, where people are using incidents like what happened in Geelong last Thursday as an example of "Autism killed that child", which is not true. The boy may have been autistic but - - -

MS SCOTT: All right. We might move on.

MR GLUYAS: Yes.

MS SCOTT: Maybe you want to go back to some of the key points that you wish to make.

MR GLUYAS: Yes. I was just making that point because it goes back to what I was saying about parents panicking because of poor information, and so on and so forth. I'm not saying that that contributed directly, because we have no evidence of it, to what happened last Thursday in Geelong. I'm not saying that at all. I am saying that, potentially, incidents of that nature can emanate from a poor evidence base and just a basic mess, shall we say, of the system.

I'll just go to another point here. On page 12 in the draft report you make reference to - yes, in the second dot point it says here:

> The mental health system would assist the many people suffering psychological and psychiatric conditions, where these did not require regular daily supports.

The way I read that, that assumes that the mental health system in this country is okay and I disagree with that. The mental health system is in actual fact in very bad need - and I've got a feeling, at least at this point in time, if the mental health system doesn't improve, the NDIS is going to have to pick up the slack. You were referring to borders before and I think that's a border that very definitely needs to be taken into account. From that comment it looks like it may not do that. The mental health system is not picking it up.

I want to point out that there's a common misconception that autism is a mental illness. It's not. However, having said that, there can be mental health issues that can arise out of not properly looking after the autistic spectrum itself, and along those lines. So there is a mental health factor there but it's very important to note that autism is not a mental illness.

Now, this one has got me really upset. I want to go to page 13, the third dot point. It says here about being in an early intervention group. Autism is mentioned here in brackets, saying that one group would be those for whom there would be a reasonable potential for cost-effective early therapeutic interventions that would improve their level of functioning. You've mentioned autism. Now, having said that, when we talk about early intervention, that imputes that we're only looking after the little ones. I'm saying it imputes it, I'm not saying that it does, but it imputes - certainly towards the autistic community - that people who are either higher on the spectrum, like myself, or even adults - and we do have low-functioning adults, of course, in the community - won't be looked after because they're not in early intervention.

I can be corrected on that but that's a major concern that I do have. Early intervention is important, no doubt about that, because it will in my opinion prevent the development of long-term issues associated with low-functioning autism and in fact, if it's treated correctly, may even improve their level of functioning to the point that they're no longer low-functioning. That's a good aim. We shouldn't ignore them but my core point there was I just felt the way that was written, it would only look after the toddlers and the babies who are on the autistic spectrum and they would only be noticed at that age if they were low-functioning. Generally, if they're not low-functioning, autism won't get noticed until they start kindergarten and start having to socialise with other children.

I want to point out that I believe at the moment, hopefully - and I come under III-D with the issues that I have. I did send you guys a link to an article on my web site titled Why Aren't I Working? I don't know if you and John have had a look at that in any detail, Patricia.

MS SCOTT: No, I haven't at this stage but we have got your material, so thanks for that.

MR GLUYAS: Take that into account.

MS SCOTT: Yes.

MR WALSH: You probably should - - -

MR GLUYAS: Yes, go on, John.

MR WALSH: I've got it in front of me.

MR GLUYAS: Okay, no problem. I haven't got time to go into the detail of box 2. I was going to go into detail as to how that basic layout doesn't assist those on the autistic spectrum. Some of them, of course, obviously aren't intended to; like, for example, aids and appliances and to a certain extent, I suppose, specialist employment services, although that's definitely only an option for the high-functioning. I guess guide dogs and assistance dogs, obviously that wouldn't apply to autism as well - although, having said that, there are some stories going around of assistance dogs actually being of assistance to autistic children.

Actually that wasn't what upset me the most. What upset me the most was the reference to the disability support pension, pages 23 and 24 of the report. It mentions reforms and it says here - I'm starting on page 23 and going over to page 24:

> However, some people using Disability Support Pension have potential for employment - with the associated gains of higher income, social connectedness ...

et cetera. I take a bit of an issue with that, chiefly because - and I did mention that not only in the Why Aren't I Working? article but I also mentioned it in my original submission, number 195, that for me personally to get back into the workforce there are certain things that do need to be done. One of the most important ones, in my opinion, is to make it harder for employers to access the unjustifiable hardship clause of the Disability Discrimination Act. I've been a victim of the abuse of that, which I have referred to in the Why Aren't I Working? article and it involved the CMO as well in that particular scenario.

Reforms of the disability support pension, in a manner of speaking I don't agree with as long as the employment supports along the lines of what I was talking about, and whatever other else is needed, aren't kept up, because that's just like saying, "Okay, you might as well just put us back onto Newstart," which would not provide the supports that would be required either. I'm seeing a black hole there. I hope you're getting what I'm saying there. I'm seeing a black hole in between the two if reforms take place on disability support pension that don't allow for the presence of a disability. Newstart allowance does not allow for the presence of a disability, and nor should it because that's not the intent of Newstart at all.

There was one more thing. I can't remember what page it was, as I haven't referred to it here, but you've made reference to starting the experimentation period of the NDIS in early 2014. Whilst I respect the idea that we've got to get it right, I see no reason why the experimentation period, as opposed to the full scheme once all the kinks are ironed out and so forth - I see no reason why it couldn't start in early

2013. I'd like to see it starting sooner still, but of course we do have budget restrictions and before you guys issue the final report we will have a budget in the meantime, which of course will take care of the next financial year. So the earliest we could reasonably do it would be early 2013 under those circumstances. I would like to see this take place earlier than early 2014 purely - again I'm talking about the experimentation period, not the full application of the thing.

I think that's all I needed to say. I'm pretty sure that Murray Dawson-Smith, when he comes in tomorrow, will cover for any issues that I have missed, in particular - I don't have the figures in front of me; Murray might have them - as to how much it actually costs the community as a whole to look after autism. I think I saw a figure in the billions - don't quote me on that - which I don't think would have been taken into account in the Productivity Commission's - I think it was 6 point something plus 6.3, if I remember correctly.

MS SCOTT: That is this report, that's right?

MR GLUYAS: Yes, in this report.

MS SCOTT: That's what we say, yes.

MR GLUYAS: Like I said, I think Murray might have the figures, I don't have them with me, but that has got to be taken into account and I think it goes into the billions by itself. So I've just got this feeling that total of $12 billion - that's what you're recommending be added to what the government is presently spending, if I remember correctly - it needs to take that into account and if it's not, it's got to go up even further.

MS SCOTT: Okay, thanks for that. All right, John, do you have any questions for Philip?

MR WALSH: Just a quick one or two. I had a look at your Why Aren't I Working? paper last night. I'm just interested; you go through lots of options in there which don't seem to work. What would you see as the sort of support that a national disability insurance scheme would provide to someone with high-functioning autism such as yourself?

MR GLUYAS: Well, I can speak specifically of myself, John, and I would hope it would apply to others who are in a similar situation to me. As you probably gathered from reading the reasons, the big problem for me is lifestyle requirement, which developed as a direct result of what happened to me with employment and with the CMO. Basically, the only way that that particular mess can be cleaned up is with funding for special interests, which would be incorporated with that. That for me, personally, and I would assume for anybody else in a similar position to me, would be a mental health issue; getting functioning level up to the highest possible level that I can within the restraints of being on the autistic spectrum.

I personally feel that I'm not up to that level. I can get there. The key issue is, number 1, getting there, and number 2, consistently staying there. The consistency is the biggest concern for me. I think consistency is probably a concern for a lot of other high-functioning autistics as well. Lack of consistency in and of itself would be a break of routine, and of course routine is very important to anybody on the autistic spectrum, whether it be high-functioning or low-functioning.

I guess the importance of routine becomes more pronounced the lower functioning you go, to the point where the routine has to be absolutely hard and fast for a low-functioning autistic, otherwise you will get the most horrific meltdowns that you could possibly have. I've had meltdowns nowhere near as bad as what low-functioning autistics do have, but when I do have them, sometimes I'm able to avoid them because I know they're coming and I take the appropriate action. That's an awareness of me knowing what I've got, and that's an awareness that's not necessarily there with other autistics. That's another education issue. I was talking about the poor information and poor evidence base before. That's probably a reflection on that.

But yes, to answer your question in short, John, basically it boils down for me personally to fund the special interests as long as it's necessary, to the point where I'm in a position where I can fund them myself through the obvious method of course, and that would be employment.

MR WALSH: Right. Thanks.

MS SCOTT: All right. Thanks, Philip. Thank you very much for coming along today, and for your submission, and I guess you're going to follow this up with a formal submission as well?

MR GLUYAS: I wasn't planning to.

MS SCOTT: All right. That's fine.

MR GLUYAS: I was going to wait and see what Murray said, and then make a decision based on that.

MS SCOTT: Okay, fair enough, that's fine. Thank you very much.

MS SCOTT: Can I just check, are Natasha Layton and Peter Wilcocks actually here? Isn't that great, because I was thinking we might move forward. Philip has stayed to his agenda and on time, so we might invite you to come forward now, if that's fine. Thank you very much for coming along today. If you'd like to identify yourself and I'm just checking - you're representing yourself? Is that right?

MS LAYTON: That's right. I'm Natasha Layton. I'm an occupational therapist, a member of the OT Association, a member of the Aids and Equipment Action Alliance in Victoria, and the National Aids and Equipment Reform Agenda, so those are groups to which I belong, but I'm representing myself today. I'm also speaking on behalf of Ricky Buchanan who is an assistive technology user, and we wrote a very short piece that has come to you. Peter will introduce himself.

MR WILCOCKS: Peter Wilcocks. I'm a polio survivor, very interested in the use of orthotics and other assistive technology, MS visitor and member of varying committees in the polio network, so that's who I am.

MS SCOTT: Thank you very much. Off to your statement, please.

MS LAYTON: Thank you for the opportunity to come and speak today. We've read with great interest the draft reports in full, and it's very exciting. I'm a PhD student at the moment. My topic is use, costs and benefits of assistive technology in Australia, with a particular focus on cost-effectiveness, so this seems a great opportunity to really deal with quite a broken system. We'll be quite brief today; three points to make.

One is that the draft report discusses aids and appliances. In box 2 a number of enabling solutions are listed that will make a difference to life for someone with an impairment. They're very broad, and we absolutely congratulate the Productivity Commission on such a broad, inclusive approach - things like domestic assistance, personal care, community access, respite accommodation. I'm talking particularly though about what's commonly known in Australia as aids and equipment, or the more current term from North America is assistive technology. The Productivity Commission has used the term "aids and appliances", and certainly "invalid aids", "devices". Terms like this have been used and are known. I don't want to play with semantics really, but I would urge the Commission to use a word that is going to really be futureproofed. If that's aids and equipment, then so be it.

We'd like to draw the Commission's attention to - Ricky and I have been trying to benchmark state aids and equipment funding schemes across Australia. Not all that information is publicly available and, for example, in Victoria less than 13 per cent of the devices that are available on the market to assist people with disabilities are actually funded and provided in part by the Victorian Aids and

Equipment Program.

MS SCOTT: That's 13 per cent?

MS LAYTON: Yes, just under 13 per cent. We have sent to the Commission a report that came out of my PhD research and I'm happy to table a published copy here, the Equipping Inclusion Studies, which talk about the extent of coverage of aids and equipment in Victoria. There is an international standard, ISO 9999, "Assistive products for persons with disability - classification and terminology", which lists all the assistive devices that are available in the world, and we would urge the Commission - this may well be beyond your remit, but this is an opportunity to advise those systems which will still be dealing with people who are not deemed early intervention or who have not got severe and profound disability, and are not included. The situation needs to be improved for them.

MR WALSH: Natasha, can I just interrupt there for a second. It's great that you put one in about Victoria. You mentioned you've been benchmarking the state schemes.

MS LAYTON: Yes.

MR WALSH: Is that information available?

MS LAYTON: It's unpublished at this stage. We're still trying to get the WA list which is commercial-in-confidence. OT Australia has been assisting us with this process, but we have comparative lists benchmarked to the ISO for every state and territory apart from WA, and it's interesting because most state and territory aids and equipment programs have been reviewed at some point, many of them multiple times over the last few years.

MS SCOTT: Yes.

MS LAYTON: What's beginning to happen is there's understanding that you cannot just prescribe things that are on a list. People's needs are individual; they are overlapping, invariably. We've found in our research 66 per cent of the 100 people we looked at used elements of personal care, elements of environmental interventions or home mods, elements of aids and equipment, and they were best provided together; in fact, cost-ineffective to provide separately. Very happy to furnish that information to the Commission. It's unpublished and unfinished, and we're unresourced, so - - -

MS SCOTT: We would certainly welcome getting it. Can I just check. You've talked about the need for flexibility, and I appreciate that, but because the scheme needs to ensure equity, and obviously has to have boundaries because of cost, I think you can imagine that there would have to be some sort of list, because you could otherwise get into all sorts of interesting robotics. I mean, we have had it pointed out to us by someone who's running a scheme overseas that if assistive technology is taken to its furthest extent, people could be looking at millions of dollars of robotic technology. So are you comfortable with the fact that there would need to be a list? There might need to be flexibility around it, and the use of the list may need to be flexible, but are you objecting to a list per se?

MS LAYTON: I think an interim step will be a list that is much better than the list there is now. Ideally, the list needs to be that which will enable function across life areas, and if that is administered well and if we have a life outcomes approach to the sort of outputs from this equipment, then I think it's manageable. With the Victorian study we looked at what is optimal prescription, because everything is what is the least costly, what is the most affordable solution - rightly, because government has to manage its resources.

When we looked at what is optimal - and some of the people in this room have been part of that research - "Costs aside, what would enable you across life areas?" and we use the ICF to make explicit what that would be, we found people were extremely modest in their requests. We also found that there was a justifiable equity weighting that should be probably applied in the case of disability, as it is now being researched for Indigenous health. So an equity weighting formula working with quality-adjusted life years would be perhaps two to three times what is a current QALY. So if a QALY is $50,000 currently, our economists found that for many of the people we surveyed in a pre and post situation, $150,000 would in fact provide them with optimal sets of assistive technologies going forward, and there would be measurable outcomes from that.

MS SCOTT: Okay. I think that aspect I need to do a little bit more reading on to fully understand the last point you made but, John, you're across some of this material. Did you understand the point?

MR WALSH: Yes, I do, and I'd be interested in having a look at it. I think that the more tangible it is the better. I think a lot of this QALY stuff can be pretty subjective.

MS LAYTON: And QALYs were hugely problematic to me in terms of how they devalue. They looked at what is normal and looked towards normal life, so problems there.

MR WALSH: Sure.

MS LAYTON: Perhaps a more practical example, and one that was submitted just for this Commission today, and then Peter can talk about his experience with one particular piece of technology. Frequently in rehab, when you are prescribing equipment, we get to tick off mobility with our prescription of a wheelchair. My argument is you can tick off much more than mobility. If we look at a device like the stand-up wheelchair, which is costly - they start at $26,000 and go upwards from there, and the Aids and Equipment Program here provides $1250 towards a wheelchair, so a fraction of the cost - you may actually be able to, with that device, allocate the benefits of that across a variety of life domains.

So if we took the ICF, "Community, social and civic life": culture, you can get a view at the Grand Prix; spiritual life, you can stand to worship; political life, you can use a standard height voting booth. This has implications, of course, to the requirements in communities to make them accessible. There are nine life domains. I've listed about 14 life outcome areas in the things I've given to you. I won't perhaps read them all out now.

There is now some literature on the cost of non-social environments, and perhaps we should change our formulas so that we are looking at genuine benefits in outcomes that are meaningful to people. I'd like to hand over to Peter, who has an example around a caliper. When I first met Peter he was requiring crutches, walking stick, scooter; difficulty taking his daughter to school, et cetera, and how one piece of technology - and just how that was costed and what his outcomes have been.

MR WILCOCKS: I have a weakness in the quads on both legs but predominantly in the right side. It got to the stage where I couldn't walk very short distances. My general health then deteriorated as well. I was using a wheelchair quite often to get out and about. As you can see, I can now walk. I'm using what's called a ground reaction ankle foot orthosis, which basically walks for me. It's a mechanical device. I'm very fortunate to have been able to be suitable for one and also to be able to supplement the cost of getting one.

The eventual device will probably come in at $6000 to $7000. The Aids and Equipment Program covers the first $2200 of that. The rest of it needs to be found by the person who is using it. I am fortunate to have a little bit of super I can tap into to cover that. The ongoing costs of maintenance are critical. It needs to be inspected at least every quarter, and the replacement costs of the components on that are in the vicinity of $200 to $300 each time. None of that is currently covered under any of the schemes. The work and the services by the orthotist are not covered under Medicare or any other scheme. I don't really understand the reasons. My point is that unless someone has other income other than the disability pension, they will not be fortunate enough to get the help that I'm getting.

I currently have a motorised scooter that most of the time sits in the shed at the back. I only use it when I go visiting the nursing home, because it's some distance away. I've given my wheelchair to a friend to use. I very rarely use crutches. I can walk up and down steps, which I couldn't do before. I've just walked from over where the girls' school is over there. That wouldn't have been something I could have done. So my involvement with the community is far wider than it has ever been.

MS SCOTT: What's it called again?

MR WILCOCKS: It's called a GRAFO, which is a ground reaction ankle foot orthosis.

MS LAYTON: Patricia, we have a letter from Darren Pereira, who is an experienced orthotist who has worked with Peter and me, and he has actually put two pages together on the outcomes of this equipment, and lists of what they cost, and what's funded and what's not. We'd like to table that.

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

MR WILCOCKS: Among many things, Darren Pereira from NeuroMuscular Orthotics is also a consultancy to the Australian Paralympic Committee, and was at the Royal Children's Hospital and St Vincent's Hospital for a number of years, and has great expertise in that area. He also works in New South Wales and the ACT, and can see discrepancies in funding available.

MS LAYTON: He comments that inequity across state boundaries is huge. Two more very quick points, if we may, and then we are finished. Peter mentioned maintenance and follow-up soft technologies. Hard technology is your device, is your piece of equipment; soft technologies refers to all the human factors surrounding that that are essential for successful use, so that could be collaborating with a therapist to come to a decision as to what's required, customising, trial in the home environment, set-up, modifications, maintenance and so on.

People are left with equipment. I've reviewed equipment that has been with people for five to seven years, which is the expected length of time a wheelchair will last in Victoria; has never been serviced; and there's no plan for replacement. You have to wait till it wears out, and then you are on the list, and then you're waiting 18 months for the new one. So from a cost-effectiveness point of view, many principles of depreciation, et cetera, are not at all adhered to there, and the NAERA - the foundation document NAERA; National Aids and Equipment Reform Alliance - have put in a submission which deals with some of those pragmatic things.

My final point with regard to the list - and Ricky has a story with regard to this. Ricky is someone who is bedfast and runs a web design business from home; she has a chronic illness. She has had a bed bath for 10 years and wanted to have a different way of showering. I would have had to apply on the Aids and Equipment Program for a $2400 shower trolley and modifications to her bathroom.

What she actually found on the Internet was a bed spa, which is a rolled-out bit of plastic you put on your bed. You tilt the bed - it's got a little camping pump and a bucket - and you put some soft wash in the bucket, and she is showering herself, and lying. That was $US200 and could not be funded because it was not on the list, the Aids and Equipment Program. So if we're going to have a list, let's have a little caveat.

MS SCOTT: Yes. All right. I've got the list message. That's a very interesting example that you use. Talking about lists, we've raised a few questions. John, if I might just have the floor for just a minute or two and then I'll hand over to you.

We raised some questions at the end of the overview about areas of difficulty, areas of challenge we had in writing the report. This might be beyond your area of comfort, but one went to the issue of prostheses - you know, artificial limbs - and should they be in or out; what constitutes an artificial limb. So back to lists again, unfortunately.

Of course, so much technology now can be - I mean, replacement of hips, replacement of knees. You don't have to be a person with a lifelong disability to be in that sort of category, and they are covered effectively by the health system, or covered by the health system, whether you think they are effective or not. On the other hand, what are the appropriate arrangements for prostheses? Do you have a view on that, given your exposure to these issues and looking at other lists?

MS LAYTON: I do have a view, and one always worries, with a view, that there will be some sort of repercussions somewhere down the line, but that's your issue to sort out.

MS SCOTT: Yes.

MS LAYTON: For what it's worth - and this is having spoken to a number of OTs who work in the area of amputees, and also the rehab engineers, who have a great deal to say about this - we would advise the Commission to again turn to the international standard and chapter 6:

> Orthoses and prosthetics: orthoses and orthotic devices, and prosthetics and prosthetic devices, are externally applied devices used to replace,

wholly or in part, an absent or deficient body part.

So for us, we would say if this is externally applied, that's one tick; that's one valid reason to include that, because things broadly assist humans. You know, we are very diverse.

MS SCOTT: Yes.

MS LAYTON: That sets it apart, perhaps quite helpfully, from some of the internal prostheses.

MS SCOTT: Except a cochlear ear.

MS LAYTON: Cochlear is listed in here also.

MS SCOTT: Separately, yes.

MS LAYTON: Yes, as it has an external element to it.

MS SCOTT: It does have an external element.

MS LAYTON: But are we nitpicking there? I suppose as an OT what I'd like to see is: what sort of outcomes are we gaining with this? Clearly, if you have a stent in your heart it affects your capacity to do most things in life, but with the majority of the orthotic and prosthetic devices, you can actually articulate the outcome in terms of how that body needs to move in an activity and participation sense.

MS SCOTT: Thank you very much for that reference. Chapter 6, you said?

MS LAYTON: Yes.

MS SCOTT: I've got that. That's good. John.

MR WALSH: I'll follow the same track a little bit, Natasha, and this is likely to get a bit difficult. How would you rate things like functional electrical stimulation, where internal basically electrical impulses are used to improve functioning?

MS LAYTON: There's a debate about this in the therapy world, of course - occupational therapy, physiotherapy - at the moment. I've largely seen that used in rehab settings and therefore it's dealt with by Health. Again, with my view of the person as a set of body structures and functions and personal factors that it needs to operate in this world, which may or may not be enabling or full of barriers, whatever it takes to increase that person's capacity to participate in life outcome areas is in, is reasonable.

Maybe when we talk about things like FES, or some of the robotics, what's very off-putting is the idea of what these devices cost. There has been very little done on the supply chain. We need to protect our small providers, particularly providing things in Australia for a very, very small market. I'm sometimes staggered by how much aids and equipment cost. I think that probably some attention to the supply end of the production there. There's been a very good article written by David Hobbs in the Australian Health Review several years ago. I'm saying that there really should be a - whatever those centres where you bring in research, development - - -

MS SCOTT: Centres of excellence?

MS LAYTON: Yes.

MS SCOTT: CRCs.

MS LAYTON: A CRC around that. That's a sort of elliptical response. As an OT, I'm continually blown away by what people can do when they have sufficient enablers, and I think everything should be looked at.

MR WALSH: If you've got any information on cost-effectiveness or cost-benefits of things like FES or robotics that would be useful.

MS LAYTON: I will go back to the rehab engineers, who will be delighted to furnish you that.

MS SCOTT: All right. Thank you. I've exhausted my questions. John, are you finished with Natasha and Peter?

MR WALSH: Yes. That was good.

MS SCOTT: Thank you very much, and thank you for providing the extra resources. We will be in contact, I think, regarding your unpublished material because that will be good.

MS LAYTON: Yes.

MS SCOTT: Thank you. Thank you for agreeing to come forward a little bit earlier than we expected. We are now going to take a break. John, does 20 minutes sound all right to you?

MR WALSH: Yes, good. Thanks, Patricia.

MS SCOTT: All right. So we're going to have a break for morning tea now. So if you've just arrived, we've sort of jumped a little bit in our schedule. We're going to resume at as close to 11 o'clock as we can. We are going to start back with Barbara Robb, and I think someone else is accompanying her.

MS SCOTT: Right, thank you very much, ladies and gentlemen. We're going to now resume. We're just a few minutes over time, and I'm pleased to welcome to the table Barbara Robb and Lachlan. Barbara, are you speaking on your own behalf?

MS ROBB: And Lachlan's and his family's.

MS SCOTT: All right, thank you very much. Would you like to make an opening statement?

MS ROBB: Yes. I'm the grandmother of Lachlan, and I've been involved in the carer movement - because I have a son with schizophrenia - for many years. When Lachlan and his twin sister were born, they were born almost four months early, and I've watched my daughter struggle with a severely disabled child. Lachlan's twin sister died when she was eight days old, and he had four months in hospital. He has quadriplegic cerebral palsy. He can't speak, but he does like to communicate, and Lachlan, you could say "hello" by pressing that button.

LACHLAN: Hello. My name is Lachlan.

MS ROBB: So Lachlan is learning to communicate using a book with symbols in it, and his family recording messages for him. I wanted to highlight today some of the issues facing young families, because most of them don't get the opportunity or the time to actually speak on their own behalf. The issues around caring for a child as severely disabled as Lachlan, as well as doing all the other things to support family, is really a major issue. Do you want me to keep going?

MS SCOTT: Yes, please. Yes.

MS ROBB: One of the things I wanted to say, one of the issues I wanted to raise was the idea that in some ways I believe we are creating disability by resuscitating and giving high levels of care to extremely premature babies. Now, I find that that's an issue that's very difficult for families to raise. Lachlan and his twin sister were born following three years of IVF treatment, so I think when suddenly one minute you're in your boss's office having a meeting and the next minute you're rushed to the women's hospital and the doctors are trying to prevent the premature birth of your twins, you're not in a position to make a fully-informed decision about whatever medical information you actually have to process. It is only after you've cared for a disabled child that you actually get an idea of the huge impact that it has on your financial life, your relationships, your social life, your work and all the rest of it.

So one of the things I'm sort of wanting to raise as a grandparent is that at the moment, if we have public policy which says we are going to use huge medical resources to save 22, 28-week babies, which is currently happening, if we do that, then at least what we should be doing is ensuring that we've got the services and the financial support to help them for the rest of their lives.

When we were told Lachlan was going to have the highest level disability you can have, would need lifelong help with all sorts of things for the rest of his life, we decided as a family we wanted to do everything we could to maximise his abilities, and we were told that he would never walk or talk. When they did the brain scan, they could just see holes which were to do with his vision processing, to do with his arms and his legs, so that when he tries to move, he doesn't have control over his movements: very weak muscle tone, poor head control, weak swallow reflex. Because he was a prem baby and tube-fed for four months, when he gets sick the doctors had trouble getting a tube down to feed him. He's had botox treatment. He's got thousands and thousands of dollars' worth of equipment that he needs just for everyday functioning.

I'm a former lecturer in social work at the University of Melbourne. I have trouble understanding how to find and access adequate services, adequate equipment and adequate funding. If I can't do it, I don't know how other people with non-English-speaking backgrounds, with single parents - because let's face it, if you've got a severely disabled child, the risks of your marriage breaking down are extremely high, and the financial burden is huge. My daughter went back to work when Lachlan was about 18 months old, or a bit less than that - 15 months old - two days a week with the ANZ Bank, who I've got to say up to now have been a fantastic employer, and very supportive.

We stepped in to do a lot of the assistance. He does go to a normal day care centre, and the other children there absolutely adore him. The woman that runs the day care centre has a 15-year-old with cerebral palsy, so that centre actually gets working with disabled kids, which we think Lachlan is a very lucky boy to have the family support and the financial resources, and we think he's a very bright little boy. We didn't know what his intellectual capacity would be when he was born, but he's showing us that he can do all sorts of things with the kind of level of help we give.

My daughter discovered that there's only one specific cerebral palsy service in Victoria for children under five, and that's the Cerebral Palsy Education Centre at Glen Waverley. We take him there twice a week. I take him Wednesday mornings. My daughter takes him Thursday afternoons. It's a four-hour intensive session which I find I'm exhausted and he is too when we've finished. It's integrated physiotherapy, speech therapy and occupational therapy.

The program actually costs something like $17,000 a year per child to run because of the intensity of the training that we're giving them; there's always a staff member and a parent or a carer with the child to help do all the exercises. We think that's been an amazing opportunity for Lachlan but I think - well, I'm able to be really angry about the fact that the program is underfunded by $12,000 a year. So the government gives $5000 a year. Every family is told that they have to fundraise, so I've brought along my little jar today to rattle. We have to walk around with a tin can in all sorts of places, we have to do all sorts of things, to fundraise that $12,000 a year for his program. That's before any of the other equipment.

The chair he's sitting in is worth about $10,000. He needs a standing frame because children under five will have major - he's already got the beginnings of hip problems. If he doesn't stand up for an hour or so every day - we've got to find all that equipment. He needs splints for his hands, he needs all sorts of things to assist with daily living, and he needs them at home and at child care. Finding the things that he needs is one thing. Once you've done that, I would say it's a permanent part-time job for my daughter to fill out forms, trying to get the equipment funded.

Lachlan has a little sister, who's 14 months old, who was conceived out of the same batch of little frozen embryos that he came from, and first go instead of taking two years. She's 14 months old and my daughter has just returned to work again, this time to find there's been a restructuring and in six or eight weeks' time she's probably going to be packaged out. It's going to be then very difficult for her to find a part-time job with the salary level that she had at ANZ. It will be just about impossible. One of the reasons we pulled out all stops is to help. I think Lachlan is saying - have you got something to say? Would you like to press your button? Do you want to press your button? We have to be slow and patient.

LACHLAN: Please can you help me get a National Disability Insurance Scheme?

MS ROBB: And he agrees with that. You can see that was daddy this morning, wasn't it? I'm going to take Lachlan out of his chair. One of the things I wondered about was whether the Commissioners would like to actually hold Lachlan, to get a little feel of what it's like to have cerebral palsy and the issues that families have in constantly attending to him. One of the things Lachlan is learning to do, which is going to help all our backs long term, is he's learning to stand up by himself so we don't have to lift him as a dead weight. So, Lachlan, I want you to stand up, darling. Stand up. That's right. Good boy. Because he's very stiff and has poor leg control - there you go. Would you go and say hello?

MS SCOTT: Hello, Lachlan.

MS ROBB: Yes, there you go. So when you have to carry him he doesn't bend in the middle. He doesn't cling to your hip the way other children do. You need two hands, one to support the head and neck and one - so everything he does he needs assistance with. He doesn't bend in the middle.

MS SCOTT: No, he doesn't bend in the middle. I'm not used to not bending in the middle.

MS ROBB: What we're doing is reprogramming his brain to learn how to do things correctly by this intensive therapy that we're doing.

MS SCOTT: Barbara, I'm about to lose him if we don't - - -

MS ROBB: Yes, all right. So what we do is we have to kind of do a bit of forcing into that - - -

MS SCOTT: Forcing?

MS ROBB: You don't like that with somebody else. All right, are you going to come to nanny? No, you're going to do that? So what we're saying is that all of this therapy that we're doing now, we're doing in the hope that we can maximise his potential. That's going to help us with everybody's backs long term because families - by the time these kids reach their mid-teens most family members have got bad backs, most family members have got poor health, many marriages have broken up, siblings have been neglected. Housing is an issue, work is an issue, having a social life is a major issue.

I don't know what the answers are to a number of the questions I'm raising. One is I think we should be having a community debate about resuscitating and giving high levels of care to pre-28-week babies. You know, I really think in some countries - - -

MS SCOTT: He's gone all funny. Barbara - - -

MS ROBB: Yes, I'll take him now.

MS SCOTT: Barbara, John is probably not seeing Jarad, though, but if you - - -

MS ROBB: Can you wave to John? Hello, John. You say, "Hello, John." You like television, don't you? You say hello.

MR WALSH: I've lost the video.

MS SCOTT: You've lost the video? Bad luck, John. It turns out the video has gone at his end.

MS ROBB: Right, okay.

MS SCOTT: But if you'd like to take a seat again.

MS ROBB: So, really, on behalf of the young families with small children, what we really need is a disability insurance scheme which gives people entitlement. At the moment the parents of these kids have no idea what they're really entitled to. When they get together and they talk about it, they don't understand why kids with autism get $12,000 a year and they get five, when it seems that Lachlan's issues to do with communication are huge and they're expensive. His book, which we use to help him develop language and to help him communicate, will eventually turn into a computer and we think that he'll be able to communicate quite well long term. That's a very expensive process and these families need help with things now.

My daughter discovered, in a conversation with DHS, that he is probably going to be eligible for an individual support package. In fact it's sitting there, I think, but they don't want to give it to him until he's four or five. That came out in a conversation. So what that means is, until that package comes through, my daughter has to go to two or three different funding sources for every bit of equipment. She has to jump through hoops and fill out paperwork and do all that on top of trying to work part-time because they have a mortgage, like most other couples, and she should be spending time with her two little children, not filling out paperwork.

So we need a scheme which makes it a sense of entitlement that covers the needs of these young children, and I believe that expectations are often too low of what these kids can achieve. Given resources at this early stage, it's going to be helpful for everybody if long term Lachlan can stand, push a walking frame around, communicate using his book or a computer, or whatever else. He says some words. We think he's a very clever little boy. He's learned to toilet train himself, he's learned to drink out of a cup, when most of the children with his level of disability are PEG fed. All of those things long term are going to save the community huge amounts of money and we think the zero to fives are the forgotten group in some ways.

MS SCOTT: I note the material you gave us just before giving your presentation, Barbara, includes lots of equipment. I've got the text, I will read it later, but just briefly for the record, how much of this equipment has been provided under government funding and how much would have been provided by your daughter and family?

MS ROBB: I guess what the government provides is 5000 out of the 17,000 for the CPEC program.

MS SCOTT: Yes, got that one.

MS ROBB: He got a hospital bed funded by two different sources of funding. One was government, one was not - you know, was a charity. My daughter would tell you more about exactly - - -

MS SCOTT: No, I'm just intrigued. I mean, the financial imposition on the family you've already indicated would be considerable. People are often amazed when I explain to them in government circles that basic necessities have to be the subject of charities and people going down to the Rotary Club or the Lions or whatever.

MS ROBB: Yes.

MS SCOTT: I'm just interested in where the equipment was provided from.

MS ROBB: The Lions Club out at Glen Waverley provide a lot of equipment. Lachlan has a little corner chair that he sits in. He has arm wraps and leg wraps to isolate muscles.

MS SCOTT: Yes.

MS ROBB: We have to pay for those. The switch we have to pay for. He has two sessions of additional physiotherapy every week; you can see his little arms don't stretch out all that well, but they're much better than they were. His hands were in that position. With the physio and all the rest of it, what we're doing is enabling him to be able to grasp. He can finally suck this thumb. He's got hand splints. He's got very flash looking - - -

MS SCOTT: I saw the leg splints, yes.

MS ROBB: The things on his feet - he's got new ones. He chose them himself. They've got a skull and crossbones on them, and they're black and white because he's a Collingwood supporter. You like the footy, don't you, Lachlan?

LACHLAN: Yes.

MS SCOTT: Yes, all right.

MS ROBB: So one issue is that often if you work hard enough you can get quite a bit of funding towards the things you need, but to do that you might have to spend 10 hours a week doing it: writing applications; putting together videos; putting together his medical history; putting together all that stuff. So you can get funding, but it's not clear where: all the families, when they talk to each other, try and help each other, but one family will get $2000 and the next family will get $200 and they don't really know why.

MS SCOTT: Yes, all right. John, do you have any questions for Barbara?

MR WALSH: Yes. Barbara, just the same sort of question. Of the direct costs that need to be spent to support Lachlan, equipment, et cetera, would you say that the government has provided a half, a third? Just ballpark off the top of your head.

MS ROBB: Probably half. I would say probably half.

MR WALSH: Yes.

MS ROBB: They've provided quite a lot of respite which I haven't talked about yet.

MS SCOTT: Yes.

MS ROBB: Respite is another essential thing. That's fluctuated. They've provided quite a lot of respite. The Commonwealth provided a special additional respite when my daughter was pregnant with her next child after Lachlan, because she had to have a stitch in her cervix sitting there for six months and not lift more than one kilo - so she could never be alone in the house with Lachlan - and the Commonwealth respite service provided considerable amounts and got us through - thank you very much - a very difficult pregnancy.

MR WALSH: My second question relates to that. We're trying to find a balance between what an insurance scheme should provide and what, if you like, natural supports are. Do you have a feeling for how much support your daughter and your family need to support Lachlan - from third parties - and how much you would like or you feel is appropriate to provide yourself, by the family? If you didn't have to do 10 hours a week of filling in forms, what sort of natural support, family support, do you think is appropriate for a child like Lachlan?

MS ROBB: We have Lachlan one night every week. That's a huge help to my daughter, because Lachlan has a startle reflex which stops him from sleeping adequately, and he also has seizures, which means he can't be left alone without a baby monitor on. He doesn't have a loud voice, so they sleep with a baby monitor. They have to get up two or three times a night to him. So we're happy, as grandparents - I think she's fortunate that we're close by and we can do that. Many families don't have that, however.

I want to be a grandmother. I know when my daughter moved into her new house into a different municipality they downgraded the level of respite because they could see I was around helping. I got really angry at that and said, "Stuff it, I'm not doing any more. I want to be a grandmother. I want to have time to play with

Lachlan, to take him to the zoo, to do those grandmotherly things. I shouldn't have to be doing the washing, the carrying, the lifting and all the other things which are a direct result."

The other side of the family have already been burnt out by the extra burden of care. They do nothing now. The other grandfather and grand-stepmother do nothing at all - financially or practically - to help. So it's up to my husband and I to do that. In the three and a half years since he's been born my husband has had prostate cancer and a heart attack. We've kept going with our level of care, but long term we can't do it.

I think respite services shouldn't be called respite. I think I've said in my little notes to you that "respite" gives the idea that someone is having a break. Basically what respite is used for in young families is, when they have date night, my daughter and son-in-law go to the supermarket together and do a big shop, because how do you do a big shop with a child in a wheelchair and another little one? It's very difficult, when you're giving 24-hour care. Lachlan is much bigger and stronger and better now, but he's needed really intensive assistance. He gets sick a lot. That's happening less often. It's all hands on deck when he's sick, but for day-to-day things the level of respite is grossly inadequate.

For kids like Lachlan it's usually about four hours a week, if they're lucky, and what's more, it's not permanently funded. So they get a good carer and then the funding runs out and she goes somewhere else, and then they get another lot of funding and then they get another lot of carers. It's ridiculous. They have to train someone how to hold him, how to feed him, how to position his body, how to use his communication book, and it becomes impossible if you don't have good-quality, long-term - I call it family functioning money, not respite money. So it is really ridiculously underfunded in terms of respite.

My daughter basically uses her respite 7.00 to 8.30 in the morning on the two days she goes to work, because there's no way you can get out the door at 7.30; it takes Lachlan two hours to go through his morning routine. He's now drinking out of a cup instead of a bottle, so that's decreased the time, but his swallow reflex is very poor so he's a slow eater. He has to be positioned in his body so that he doesn't aspirate, because then he'll get pneumonia and end up in hospital. Two hours just to do that. You can't do it with one person and look after a 12-month old. She, in contrast, can hold her own bottle, feed herself. She only eats what she can feed herself at the moment. She can entertain herself. She can move. You put him on the couch and he'll flop over. He can't sit up by himself. He's a floppy little boy.

You really need a lot more services in those first five years, largely - what happens to the rest of the family? Little Eliza, his little sister, has been a perfect baby, I've got to say. She's been really easy. She was full-term. Really easy, slept well. You put her in the cot and she goes to sleep. She's now starting to hand things to Lachlan and, as I say, she's done everything else, but it's not fair on her. One of the reasons she's so well behaved is because she's never had a mother who can instantly go to her and give her things.

If there's ever another child in the family - and some of the families have older siblings who need to be taken to sport - how do you do that if you don't have someone who can stay in the house? Otherwise you're trapped in the house with these kids without - and it's not respite. It's family functioning money that they need, and time. Then, if you get that right, maybe they could have a date night once a month. But at the moment the level of respite is grossly inadequate for normal family functioning. No wonder marriages break up at a very, very high level.

MS SCOTT: All right. Barbara, thank you. John, any further questions for Barbara?

MR WALSH: Thank you, Barbara.

MS ROBB: Okay.

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

MS ROBB: Thank you.

MS SCOTT: Thank you for bringing Lachlan to be here at our public hearing.

MS ROBB: Thank you. All right. What do you say?

LACHLAN: Thank you for your time today.

MS SCOTT: Very good. I'm sure Jarad has got that. That's very good, thanks.

MS ROBB: It will take us a couple of minutes, I'm afraid.

MS SCOTT: That's fine. We've got a few minutes. That's all right.

MS ROBB: Thank you. Now, the other thing I meant to say to you, I decided that one of the ways to proceed with fundraising - we make jam. I thought we'd use it as bribery and corruption money. There are some jars of Lachlan's raspberry jam. Thank you very much. We usually sell them for $10 a bottle, but for you they're for free.

MS SCOTT: I wish I had my assistant here to tell me what the legal implications are.

MS ROBB: I'll go to gaol, don't worry.

MS SCOTT: I think I'd be the one going to gaol. Thank you very much.

MS ROBB: Thank you, but that's the other thing: we feel they've got enough to cope with without fundraising, so thank you.

MS SCOTT: John, some more jam for Victoria, I think.

MR WALSH: Patricia, enjoy it.

MS SCOTT: I now invite John Barnett to come forward. John, thank you for coming here today. You'd like to make a statement, or talk to us about - - -

MR BARNETT: Yes, I've got a statement that I'd like to read at this stage, and then maybe answer questions.

MS SCOTT: Sure, that's fine. You've got 20 minutes.

MR BARNETT: 20 minutes, okay. I'll leave the timing to you.

MS SCOTT: Yes.

MR BARNETT: I speak to you as an individual. My views expressed are entirely independent of my employer and my disability service provider. I want to make that plain. I'll just speak of my qualifications to speak. For over 50 years I've experienced juvenile rheumatoid arthritis of gross severity. I've a massive deformity of and limitations to my skeletal structure. My University of Melbourne bachelor of arts degree with majors in mathematics was achieved while working on the bed at home in the 1960s. After an intensive three-year rehabilitation program, I learned about living a life more fully integrated into the community. At the age of 36, I gained full-time employment which I've retained for the last 30 years. At 66 I am still full-time employed. I live in my own unit, supported every day by a team of attendant carers - one of whom is here today - without whom I could not survive. I utilise a range of specialised aids for independent living.

Issues of concern in the draft report which I read - I've just got a few specific things that I'll refer to. Page 3 - I'm quoting from the report:

> A separate scheme is needed for people requiring lifetime care and support for catastrophic injuries.

And later:

> State and territory governments would be the major driver of this national reform.

But what of people who experience catastrophic injury and regain independent living skills with work potential? They would need a seamless transition from one scheme to another. Creation of a separate scheme would inevitably inhibit this. I argue for one all-encompassing scheme. On page 12:

> People with bad backs and other musculoskeletal conditions would also typically receive assistance from the health system.

It gets up my nose a little bit when my condition is clearly of musculoskeletal origin and a suggestion that it should be treated from the health system. I think that's a fault in the report. On page 46 you also say:

> Support should be provided outside the NDIS for people whose support needs would be more appropriately met by the healthcare and/or palliative care systems, comprising those who would benefit from largely medically orientated interventions including less restrictive musculoskeletal and effective disorders, and many chronic conditions.

As I said, the origin of my impairment is a musculoskeletal condition. I suggest the Commission is here confusing cause of disability with consequence of disability - namely, the impairment resulting from the disabling condition. I argue for deletion of all references to musculoskeletal conditions in the report; rather, continue to focus on the definitions of disability as exampled in page 45, which I think is effectively the target group of the Disability Services Act, which describes the eligibility for people to benefit from services under the act.

I come to the Victorian disability sector. With disability related experience from inside and outside government departments and disability organisations including self-help groups, I come from a culture of self-help, maximising personal independence, being mutually supportive, taking responsibility for my life and my future, teamwork, and contributing to and depending on the community. In 1981, at the age of 36, I won my first open employment job. It enabled me to pay taxes and get off the invalid pension, as it was then called. I am pleased to be a taxpayer, paying thousands of dollars each year in income tax. My plan is to be independent of the aged pension and very likely I will achieve that.

My life does not dramatically change at pension age. My goals and aspirations continue as they have been for the last 30 years. Regarding the reaching of pension age, page 15 says:

> Upon reaching the pension age, and at any time thereafter, the person with a disability would elect to stay with the NDIS or move to the aged care sector.

On the same page, the report adds:

> Either way, after the pension age, the person with a disability would be subject to co-contribution arrangements set out by the Commission in its parallel study into aged care.

For this inquiry into disability care and support, not being explicit about how those co-contributions would be calculated is simply not good enough. If co-contributions are to be recommended, the report should say explicitly what they are. Would such co-contributions be capped, or have an excess or other limitations put on them? Page 16 the report adds:

> The aged care sector would fund the care and support needs of all people over the pension age. If a person elected to continue to use the NDIS care arrangements, the assessment tools from that system -

well, I don't know whether you mean the aged care system or the NDIS system -

> would be used to determine their funding, and the person would continue to receive support through the NDIS.

The draft report needs clarification on these matters. I currently receive 34 hours a week support, spread over the seven days. What guarantees would I have that this allocation of support hours would be maintained if aged care assistance and funding sources were involved? For people with individualised funding packages, who now buy their disability services, will those amounts remain if they go through the perceived pension age barrier? The report should elaborate on expectations of the transition of the individual from the NDIS to aged care, if that continues to be the Commission's preferred option. Instead of pension age being the boundary, has the Commission considered for those who are passed that age, including those who are still working, being maintained within the NDIS?

That may be a more consistent approach, especially in Australia's environment of an ageing community, and encouragement for people to work longer and be more independent of government. In my opinion the functions of assessment and funding of eligible disability services must remain within the NDIS, irrespective of age. I argue for the second option referred to on page 16. A second option would be for the NDIS to continue to fund people with an earlier acquired disability, after the pension age, but with the aged care sector funding the incremental support costs associated with natural ageing.

My preferred model for funding an NDIS is taxation. We have the Australian culturally acceptable model of Medicare. Here services are free, but all taxpayers pay the Medicare levy. An NDIS funded by an additional levy on income tax would be the fairest and most equitable scheme. I'm totally opposed to also paying the co-contribution. Just because I've exceeded the pension age, hitting me with a double whammy would be most unfair. So, if you insist on a co-contribution, it should at least be tax deductible or qualify as a rebate on tax.

There's nothing about these matters said in the report, which is an omission of the draft report. I hope you will address it in the full report. Page 28 of the report dismisses the issues surrounding the GST as too difficult. Where would co-contributions sit regarding the GST - that's the goods and services tax? Would this be a triple whammy for people transitioning through the pension age barrier? Again the report fails people with disabilities and their families by passing over this issue as too difficult.

These key issues remain: a single system like Medicare, or a split system; NDIS and aged care. Wherever you have a split system, clients will always have difficulties at the boundaries and people with disabilities will especially experience those difficulties. I hope there is the flexibility and open-mindedness to reconsider some of these matters.

MS SCOTT: Thank you. John, do you have any questions for John?

MR WALSH: No, I don't have any questions. It's a very clear presentation. I think you may have misunderstood some of the intention in the report, first of all the musculoskeletal one. You might read that what the report actually says is "including less restrictive musculoskeletal and effective disorders".

MR BARNETT: Yes, but it still goes back to the origin of it and not the impairment resulting from it.

MR WALSH: We don't want to get into a debate today.

MR BARNETT: No. I just point that out.

MR WALSH: But we're interested in ensuring that a scheme is viable and doesn't take on all of the responsibility of the health system.

MR BARNETT: I'm not arguing that it should, but I just think you're better dealing with the impairment resulting from the condition. That is where "disability" is defined and, if you stick with that through the report, it would be clearly better.

MR WALSH: Thank you, John. I've got no more questions, Patricia.

MS SCOTT: John, just another clarification: you say a single system like Medicare.

MR BARNETT: Yes.

MS SCOTT: Of course, our health system isn't just a single system, is it? I mean, we've got Commonwealth and state funding. The Medicare levy, as we explain in the report, only funds about 10 per cent of total healthcare costs. Would you still feel the same about the Medicare levy, and do you think it would be acceptable to the Australian public, if the Medicare levy say doubled, tripled, from where it is now? Do you think that would make it an acceptable option?

MR BARNETT: You see, I think there's merit in considering that. I can't just give an instant answer. The beauty of it is that people who are more able to pay contribute more, so it's a progressive taxation; the greater you earn, the more you contribute. I wouldn't mind at all, you know, increasing the levy two or three times or whatever may be needed. But I still think, if we are really bringing in a new system for people with disabilities, we need to look at some dimensional change and not just looking at 16 to 65 or any other limitation. I'm not suggesting you necessarily are, but particularly with a disability acquired prior to pension age then I think, if support is needed, it should be carried on beyond that age. That's my main contention.

MS SCOTT: Thank you very much for your time. Thank you. That's a very clear presentation.

MR BARNETT: All right. Thanks for the opportunity.

MS SCOTT: And thank you to your assistant.

MR BARNETT: That's fine. Thank you.

MS SCOTT: All right. We are now going to have Gill Pierce from Carers Victoria presenting. Good morning. Would you like to identify yourself for the record, and your organisation, and then would you like to make a short opening statement? I think you should anticipate that John and I will have some questions for you. We've allotted 30 minutes for your presentation. Thank you very much for being here a little bit earlier. I think I'm going to be chastised for actually running the ship too tight. We'll see how we go. Anyway, 30 minutes.

MS COLLIN (CV): Thank you for the opportunity to present. I'm Emma Collin, executive manager of marketing strategy and policy with Carers Victoria, and this is my colleague Gill Pierce, who is our manager of policy and research.

MS SCOTT: Thank you.

MS COLLIN (CV): Congratulations on the reform proposals. Carers Victoria have read the draft report with considerable interest and are still analysing the content and recommendations, and gathering intelligence from participating in and presenting at a variety of stakeholder forums and we'll make a further submission.

MS SCOTT: Thank you.

MS COLLIN (CV): In addition, we are assisting Carers Australia with engaging caring families in forums to discuss the work of the Commission, which will assist Carers Australia's submission development. We are also encouraging families to submit their views directly to you. We are partners in the Every Australian Counts campaign and keep our members informed about both the work of the Commission and the activities of the campaign. We plan to limit our discussion today to a small number of key issues which for us may be contentious. We also are keen to inquire about the origins of some recommendations.

We believe there is potential for Australia to lead the way internationally by developing an integrated disability services system that is both person-centred and family-focused. This has implications for the proposed design of the NDIA, proposed funding entitlements and assessment and support practices. While high-level policy and planning must address the needs of all people with disability and their families, this may risk overlooking the key policy practices and funding differences required for diverse individuals and equally diverse families. We challenge the Commission's view about separate supports for caring families, information and referral, counselling, respite and capacity building or training. Respite needs a different conceptualisation.

MS SCOTT: Okay, can I just get you to explain a little bit more about that now?

MS COLLIN (CV): We will - - -

MS SCOTT: Later?

MS COLLIN (CV): Yes.

MS SCOTT: Okay.

MS COLLIN (CV): I'll just finish. We ask a few questions about the capacity of the market to provide. We will respond to the Commission's request for feedback on the desirability of including carer payment, carer allowance, carer supplements and mobility allowance into the NDIS. We will express concern about our understanding of proposals in relation to housing and support for people with a disability. Finally, we wonder whether proposed eligibility for NDIS and related data is excluding people with a psychiatric disability. I'll now hand over to Gill, where we'll go into those components in greater detail.

MS SCOTT: Thank you.

MS PIERCE (CV): First I'll talk about an integrated disability system that's person-centred and family-focused. It's our view that most families recognise the interdependence and interconnectedness of the needs of the family with those of the person needing support and assistance. We know that adequate support for the person with a disability can contribute enormously to an improved quality of life for families and it's not something the disability system has provided to date.

We argue that interdependence is the lived experience of most people with a disability and their families. Some Institute of Health and Welfare data - I think it's 2008 - suggests that 97 per cent of people under 65 with a severe or profound limitation live in the community. Of those, 84 per cent live with family, be that parent, partner, offspring. 10 per cent live alone and 3.2 per cent live with unrelated people - we assume probably friends. We would also say that ongoing family support, close involvement of families is common after any move to independent living, though obviously not always.

We understand that the overall objective of the draft disability care and support scheme is about enhancing the quality of life, economic and social participation of the persons with disabilities and their families, but from reading the report we think that a person-centred and family-focused principle isn't systematically applied. We would suggest an enlightened approach to disability rights needs to be applied in relation to people with decision-making disabilities and their families. Our calculation is that around 60 per cent of current National Disability Agreement service users would have decision-making disabilities - that's a rough calculation -, so that involved in their families is substitution and support of decision-making roles, direct assistance of the family member with ADLs, support in communication and social participation.

We would argue that many of those families will need an increased level of support where there's a significant level of intellectual disability. We would also argue that there's a need for joint planning and partnership as a family, both with the proposed National Disability Insurance Agency and with service providers. We think that degenerative conditions imply the need for progressive increases in formal and informal support, and they're likely to require progressive funding increases to support informal care and how is this proposed to be done.

We think, too, that the report doesn't address very well the barriers to workforce participation of caring family members, such as the critical availability of substitute care. You do address the flexible work provisions but there are other financial barriers, such as the effective marginal tax rates, that apply to people who use income security and do a small number of hours of work. Flexible work for family carers often mean low-paid and casual work and there's a lot of evidence for that.

We feel that the disability rights movement and the carer movement have created a divide between services for the person with a disability and services for their caring families, despite the interconnectedness of their needs, and it's our view that that may have reduced the efficiency of services, increased costs, increased system fragmentation and increased the number of transactions or the number of agencies that people with a disability and their families have to go to for support and assistance.

There's potential, we feel, to combine program funding for carers and for people with a disability into a single person-centred and family-focused system, thus ensuring a holistic focus on the person in their family situation, thus reducing the number of agencies involved and reducing competition for funds between the carer stakeholders and the disability stakeholders. We think that the proposed individualised funding and the allocation of respite funding to the person with a disability, as proposed in the report, is likely to lead to a reducing role for the carer support agencies as people with a disability and their families minimise the number of intermediaries involved. They will probably choose those that you use intermediaries to do that through one disability services organisation.

So the second area was the diversity of family needs. We think that there's no obvious intention in the report, as we understand it, for any layered approach to family support entitlements to accommodate families with differing needs, but there are many family circumstances where there's evidence of considerable complexity and evidence of risk to their capacity to sustain informal care.

Examples of that include families who support and assist children or adults with very challenging behaviours; families who provide high-intensity or medical care for people who may be non-mobile and require ventilation, PEG feeds, transfers and lifting; complex care situations such as those involving young people with care responsibilities in relation to their parent with a disability; families with multiple care responsibilities within or between generations - and there's a figure about the number of caring families who care for more than one person - particularly sole carers or single parents, where there's a lack of informal support from friends or neighbours, where they're socially isolated and have few roles outside the provision of support and assistance; and family carers who have disabilities or chronic illnesses themselves, and there's again a high proportion of caring family members who have disabilities and chronic illnesses.

I guess we're arguing that the National Disability Insurance Agency needs to tailor additional support for families at risk and to identify families likely to be at risk and tailor support to them. We think, too, that family support at transition is important and is, in effect, a form of early intervention. In the lifelong disability sector, lifecycle and other transitions have huge significance for people with a disability and for their families. That, as I'm sure you know, includes transition from early childhood to preschool, from preschool to school, from school to employment or further education, but it also includes crisis care and transitions to care outside the family home.

Our understanding is that the key transition points for people with a disability and their families - think about their future needs, collect information and explore available options to them, learn what will be involved, share the decision-making as far as possible, and consider what their new role and responsibilities might be. Transitions for the person with the disability need to be timely, phased-in and, in general, supported by their families. I think the availability of some transition funding can assist in this process, but that should be jointly focused on the person with the disability and their families.

MS SCOTT: Do you mind if I interrupt you?

MS PIERCE (CV): Not at all.

MS SCOTT: My recollection of the 800 pages is that there's a considerable amount of attention given to transition points, so I'm just still at a loss to work out what the issue is here.

MS PIERCE (CV): Yes, there is attention given to transition points, but it tends to be focused on the person with the disability, it sees the families as a resource rather than as having needs for support with transition in their own right. Is that answering the question?

MS SCOTT: Thank you.

MS PIERCE (CV): So what we're saying is that funding entitlements need additional weightings for assessed family risk. That's really a prevention role. There need to be short-term funding entitlements for transition and case management support focused on both the person with the disability and their family. Our written submission will include an outline of a model of care assessment which can facilitate the identification of families who might require additional support.

You asked about respite and family support. In our view there may be some misinterpretation of the need for respite support. We think that the notion of respite, vague though it is, disguises a range of needed supports for the person with the disability and their family, and that the range of needs arise in complex care situations and situations of change or risk, as I've outlined. We think that a variety of regular ongoing and adequate disability supports, chosen according to needs and preferences, can assist in the provision of family support.

It's our view that a wide variety of services provide a respite effect for the partners - or the parents or whoever - of people with a disability and ensure that caring is shared. A respite effect can result from the access of the person with the disability to adequate personal care, community access, in-home behaviour management, education, employment, recreation and community participation, travel and holidays, but they also need to be tailored to the needs of families.

Such tailoring reduces the need for formal, more traditional respite programs, and can replace the notion of respite as relief of care and burden - which I think is offensive to people with a disability - with positive opportunities for community participation by the person with the disability and their caring families. There will always be a place for episodic and crisis support respite arrangements.

Next, can the market provide? We think there are market distortions in community care in the form of undersupply for some of the high-needs groups, such as adults with significant cognitive disabilities and challenging behaviours and people with profound and multiple impairments. Cherrypicking within the market is demonstrated in relation to provider reluctance or refusal to provide services to the most vulnerable.

As we understand it, the National Disability Insurance Agency will monitor service needs and gaps and there's a proposed innovations fund. We think that within that there are issues about the initiation of new responsive individual or group programs to fill gaps in the current system, and that that will require infrastructure for community and program development. We're not sure whether that's a function of the National Disability Insurance Agency innovations fund.

We think, too, that while there are many benefits, there are also risks in individualised community access and participation, particularly the risk of isolation. Many people with a decision-making disability wish to participate in new small group programs such as recreation or small group holidays. Maybe they will require block funding to seed their initial development; some notion of outreach and a lot of back-of-house work, and we're not sure that individualised funding will address that need. So I guess the question there is: how will community and program development occur?

We particularly wanted to comment on the notion that the Commission asked for feedback on, on whether a series of carer payments and mobility allowance should be included in the National Disability Insurance Scheme. We perfectly understand the need to link reductions in income support payments with national disability insurance - and that cost offsets can be used for more support to more people - but we feel that there has been a misunderstanding in the Productivity Commission report about the purpose of carer payment, where it's defined as a payment for the care provided.

Centrelink defines "carer payment" as "payment for carers who, because of the demand of their caring role, are unable to support themselves by participating in the workforce". It's an income security payment, not a means of encouraging informal care, and often not a choice for caring families. It would be true to say, too, that other income security payments are received by some caring families, including aged pension parenting payment and disability support payment.

We wanted to comment on the proposal that people with a disability can use carer payment as a means of choosing alternative options for informal care. That's not currently precluded in the current system, where someone with a disability or the family of a person with a disability can encourage someone else to apply for carer payment in return for the care provided. We feel that that can disadvantage the whole family, that moving off carer payment means a family carer, ex-family carer, would have to move to Newstart and lose income support. It risks, in our view, undermining an appropriately paid workforce. It's another grey economy issue.

There can be exploitation of the payment of the payment recipient. We have refused to support the notion of families setting up their sons or daughters in an arrangement with someone receiving carer payment because we're aware that often what's expected of the carer payment recipient is beyond what's reasonable and there are no controls, and we think it's potentially divisive for caring families.

Carer allowance currently, we think, has a rather ambiguous rationale. There are historical reasons for that, but carers see it as either a form of recognition of their caring role or an income supplement to meet the costs of disability or caring. These needs of caring families are not currently met any other way. Similarly, carer supplements are annual payments to carers to assist with the cost of caring, and child disability assistance payment and carer adjustment payment are payments for the cost of care.

We think that carer allowance and carer supplements remain important and their removal is likely to be really politically inflammatory. It may be that, with successful implementation of a National Disability Insurance Scheme and increased workforce participation by carers, there's a future a need to review carer payment and allowance, but it shouldn't occur now.

Housing and support, in this report, includes some housing types for people but not others. We're not quite clear what range of housing and support models are included in specialist accommodation support, but we see that there's a special accom support category and other housing is seen as mainstream. Maybe that will be problematic. While specialist accommodation and support has to be included in this scheme, there may be a massive incentive to choose this option rather than mainstream housing, regardless of need or suitability.

MS SCOTT: Where do you see that incentive coming from? Who has that incentive?

MS PIERCE (CV): People with a disability and their families would want to guarantee the security of supported housing under a National Disability Insurance funding, and may hesitate to access community housing in our view, but it might be a perverse incentive. I guess lack of access to housing for people with a disability, to social housing like community housing and public housing, is really about issues about poor income due to disability, affordability and lack of supply. We're concerned about the impact of the lack of suitable social housing on the National Disability Insurance Scheme, and whether the NDIA will be able to lever improved supply of social housing, and addressing the current access barriers to social housing would be crucial. Finally, our big question is whether eligibility for national disability insurance and related data is excluding people with a psychiatric disability.

MS SCOTT: You couldn't find material in the report that helped you answer that question?

MS PIERCE (CV): Bear in mind we're still ploughing through it.

MS SCOTT: Okay.

MS PIERCE (CV): But the difference in the data from the first report and the DIG report and this report made us wonder whether - and I know the Commission has said that COAG has an interest in people with a psych disability, and so you're uncertain whether that group should be included in the NDIS scheme.

MS SCOTT: Yes. I think when you get a chance to read the relevant parts of the report, we do include some psychiatric conditions. We talk about the challenge of that in terms of taking a functional approach, and then falling back to conditions, but that reflects data limitations, but we do explicitly ask questions in the overview and in the chapter about whether it's appropriate to include those groups. The interface between mental health and the disability sector is very difficult, and we're particularly interested in that view, but I'm hoping that when time allows you, you might turn to those sections and then provide us your comments on whether what you see is the appropriate dividing line. John, do you have some questions for Carers Victoria?

MR WALSH: I'd just like to clarify, thanks, Gill and Emma: I suppose I'm interested in the expectation of what family support would look like. I think the main focus of the report as you correctly pointed out is to provide a support package for people with a disability. If those support packages were provided, I'm interested in what you would see as the additional support that families would require.

MS PIERCE (CV): Yes. Maybe I haven't outlined our views clearly, but I think there's a preventive focus in the Disability Care and Support report for people with a disability. I didn't see that that was systematically applied to their caring families, and we know there's a number of families who are more at risk than others. That's what I was talking about.

MR WALSH: Compared to what, Gill?

MS PIERCE (CV): A family breakdown or institutionalising their son or daughter or, you know, not being able to manage. It's our view that tailoring additional support to families at risk is really important, as it is important to tailor additional support around transitions where that's needed.

MR WALSH: What would that additional support look like?

MS PIERCE (CV): It would vary according to the needs of the individual situation, I think, but some families at risk might need additional in-home support.

MR WALSH: That would be in-home support for the person with the disability?

MS PIERCE (CV): Yes, perhaps. I think actually maybe we'll do some more work on defining what that might look like. That might be a good way of - - -

MR WALSH: Because if that is what you mean, I think that's covered by our proposals.

MS PIERCE (CV): All right, I'll have a look at that. I have a tension about this too. If you look at the needs of young people with care responsibilities that may be putting them at risk, then how do you support that family, particularly if the parent has an acquired brain injury, say? It's really a family support system that's needed. Does that belong in a National Disability Insurance Scheme or does that belong in a child protection family support system? I don't know the answer to that, but I think that's a group of people where comprehensive family support is needed. It may be a group where niche support programs are needed, rather than individualised funding.

MR WALSH: That's fine from me, thanks, Patricia.

MS SCOTT: I'm conscious of time, but section 4 of your paper about "can the market provide" implies that there's actually a market at the moment, and I would have thought that in most states there's in fact no market. There's just block funding, with people having almost no choice at all. Rather than suggesting that the current arrangements are market-oriented, maybe I would suggest that you start at a different place. Either suggest that we're wrong in thinking that there isn't any market - if you think there's a market, you might point to where that is, and any information you have on a real market existing. If that's not the case, then you might start on the basis of what would happen if there was a market, just as there's a market for other things now.

MS PIERCE (CV): Yes.

MS SCOTT: I'm just curious about your section on housing and support, because here you think there's going to be a massive incentive to choose specialist supported accommodation. I think I've got that. That's what you're suggesting?

MS PIERCE (CV): We're wondering, yes.

MS SCOTT: Yes, all right. I just wondered why the assessment process won't work there but you think it might work in other places in relation to other forms of support. I mean, why would well-qualified professional assessors find housing beyond their means to work out if people are gaming, but they will work in other areas, or maybe you won't have confidence about - - -

MS PIERCE (CV): Yes, that's a good question.

MS SCOTT: All right. So you might want to just - - -

MS PIERCE (CV): I'll have a think about that, yes.

MS SCOTT: These people are experienced and trained. They will be able to do that in all the other areas of the field but you don't think they will be able to manage on housing. I would just like to be able to reconcile that in my thoughts.

MS PIERCE (CV): Actually, you've just reminded me. One of the other things that we wondered about was whether there's an incentive for people with a disability and families to minimise presentation of the informal support provided to try to encourage increased formal support. Again, it's a thought. I guess you're feeling that very skilled assessors would be able to see through those games.

MR WALSH: Yes. I think that's a question if you've got any thoughts, we'd welcome input on that.

MS SCOTT: Yes. We'd welcome the input. I guess we've tried to draw on international studies where possible, and the Australian experience with some of these arrangements. We do have a requirement in the assessment process - again, when you get a chance to read the report a little bit more fully, you'll see that in the assessment process we do ask people to stipulate what the current arrangements are that they're in receipt of, so if somebody suddenly went from needing three hours of paid care to wanting 36 hours of paid care, I'd like to think that the assessment process would ask why and what's happened.

MS PIERCE (CV): Is that in the main report or in one of the appendices, the "nudge".

MS SCOTT: No. No, it's in the main report.

MS PIERCE (CV): Okay.

MS SCOTT: All right. Thank you very much for coming along today. We might move on.

MS SCOTT: Simone, would you like to give your full name?

MS STEVENS: Yes.

MS SCOTT: I think you are representing yourself.

MS STEVENS: Yes, I am. My name is Simone Stevens, I live in Geelong, and I'm a self-advocate.

MS SCOTT: All right. Are you a permanent resident here in Australia?

MS STEVENS: Yes, I have been all my life. Hi, John, how are you?

MR WALSH: Hi, Simone.

MS STEVENS: I just wanted to tell you a little bit about myself, a little bit about the problems that I'm enduring at the moment and what I would like to see in the future for myself and for people who have disabilities, if that's all right with you.

I am 33, and I was born a healthy and normal baby, but I had septicaemia when I was four months old and I developed cerebral palsy. That meant that I was like little Lachlan. I was like Lachlan up until the age of seven. I didn't have any head control or anything like that. Then, by the age of seven, I learnt how to talk. By the age of eight I learnt how to walk a little bit, so that was really good.

The problems that I'm facing at the moment: I live on my own, and I've got carer support, which I really, really need because I've got so many problems; health issues that are as long as your arm. What I'm finding difficult now, and this is what I would like the NDIS and the Commission to have a look at, is the funding; how the funding is around people with different disabilities. I mean, there's a lot for people with intellectual disabilities, and minority groups and stuff, but I'm struggling. I've got DHS and I've got my individual package, but I'm having problems at the moment. I'm needing a hi-lo bed at the moment because I'm having a lot of hip and shoulder issues. Even though I fought for my carers, who are great, I'm still wanting to be as independent as I can.

MS SCOTT: Just on the hi-lo bed, have you had advice about whether you are eligible for a hi-lo bed, or why you're not eligible, or why you'd have to wait?

MS STEVENS: We're going through that system at the moment, but I had to move disability organisations because of neglect and harassment and I had to move quite abruptly. I've just been informed this morning that if I want the amount that I was allocated last year, equivalent to about $20,000, I would have to reapply for that, which I'm fighting because I don't think people with disabilities, or families, should have to reapply for something that is rightfully theirs in the funding.

MS SCOTT: Fair enough. Just on the $20,000 package, were you part of the Victorian individualised package arrangement?

MS STEVENS: Yes.

MS SCOTT: You were?

MS STEVENS: Yes. DHS.

MS SCOTT: Yes, DHS.

MS STEVENS: Yes. I got a Support and Choice package.

MS SCOTT: Good. Because you've had this falling-out with your past provider, you now have to reapply?

MS STEVENS: Yes.

MS SCOTT: And the hi-lo bed would be in addition to the $20,000 package?

MS STEVENS: Well, hopefully that's within that.

MS SCOTT: All right.

MS STEVENS: My main concern is that people with all disabilities shouldn't have to go through hoops, shouldn't have to fight for every little single thing. At the moment, as you can tell, my voice is going up, because it's causing a lot of pressure for me, because I am my self-advocate and I am my own case manager, and I prefer it that way because that way at least I know it's done, but not many people would prefer that, and I do understand that.

MS SCOTT: Have you had an opportunity to hear a little bit, or read anything about - - -

MS STEVENS: Yes, I have. Yes, I've read the report.

MS SCOTT: Is there anything about the report that causes you concerns that you'd like us to - - -

MS STEVENS: I can't say there is. I'm quite happy with the report, actually, to tell you the truth.

MS SCOTT: All right. Lovely.

MS STEVENS: I've read through it thoroughly. There's nothing in there. All I'm wanting from that is a little bit of flexibility if the person with the individualised support package is able to do what I'm doing; is able to, say, give a little bit more direction instead of a case manager or an appointed appropriate person.

MS SCOTT: Okay. John, do you have any questions for Simone?

MR WALSH: I'd just like to understand, because I think you said you were getting 34 hours per week - - -

MS STEVENS: 20.

MR WALSH: 20 hours per week, and that's what the $20,000 package is, is it?

MS STEVENS: Yes. … my previous organisation, severely neglected my needs and left me without care for days on end, where I had to go without showers and - - -

MR WALSH: If you were asking for a package which you are designing from scratch, how many hours a week do you think you would ask for?

MS STEVENS: Realistically, for my needs at the moment, roughly 30, and that's just because my mobility is not as good as what it used to be.

MS SCOTT: All right. Simone, thank you very much for presenting.

MS STEVENS: Thank you for letting me speak. I really appreciate this.

MS SCOTT: That's all right.

MS STEVENS: So thank you.

MS SCOTT: That's okay.

MS STEVENS: And nice to talk to you, too, John.

MR WALSH: Thank you, Simone.

MS SCOTT: Thanks for that. We are now on time, on track. We're going to go to lunch and we'll be resuming at 1.30. So thank you very much. See you at 1.30.

MR WALSH: Thanks, Patricia.

MS SCOTT: Thanks, John. Bye.

(Luncheon adjournment)

MS SCOTT: Good afternoon. We're now going to be resuming the hearings. Thank you very much for taking your places. Gary Allsop has come to the table and will be presenting for a very short time as we've rescheduled the afternoon to accommodate Gary, so he understands he's on a very tight timetable. I just remind everyone that because it's a public hearing we are making a transcript available, so you might want to take that into account in making comments. I have to say a couple of people this morning sort of made some fairly "shoot from the hip" comments about other individuals. You just might want to keep that in mind: that it is a public transcript and it will be publicly available. I'd hate any of you to be the subject of a defamation action, so you just need to be careful.

All right, Gary, over to you. I imagine you've got, say, 10 minutes, and if you could identify your organisation, that would be good.

MR ALLSOP (SCA): Yes. I'm a director of Spinal Cure Australia. My main focus is spinal cord research. However, I'm doing a lot of advocacy work for people with spinal cord injuries, and the main focus that I've been sort of campaigning on is the inequality for the type of accident you have. If you are a TAC or Workcare patient and have a spinal injury, you are covered for all sorts of equipment - incontinence aids and every other aspect of your life - whereas my accident was non-compensatory as a football accident and I received no compensation. So it's been a battle to get all sorts of equipment.

My argument so far as incontinence aids, it should be distributed on a needs basis, and when you are a spinal cord injured patient and you have to have two catheters a day - which is a catheter in twice a day - and you are on condom drainage, it costs about $8 a day. If you times that by 365, it's a lot of money and it's not covered by the government. So there's a sort of inequality and not a level playing field when it comes to particularly spinal injured patients.

My catchcry to the politicians - and I've written to many of them and tried to get meetings with them; not a lot of them want to see you because they want to duck-shove the issue. My argument has been that it should be every man and woman's right to go to the toilet for free, just like every able-bodied person probably takes that for granted. But when you have to have a medical procedure done twice daily - and my mother actually does it - it's not a fair playing field for me in terms of other spinal patients who are covered for that sort of thing.

So that's been my main focus: chasing the politicians; trying to get them to sit face to face and listen to your argument. The only one I've been able to do that with is Bill Shorten - a couple of times actually - and Bill is very proactive, as everyone knows, and very sympathetic. When I told him I wasn't covered for all that sort of equipment, he couldn't believe it. So that's the main focus that I've had.

The other one is care hours. I'm in a situation now where my parents are 80 and I have to think about when they're not around. I've just turned 50, so I have to think about a plan to put in process to try and get some hours for someone to come and put me to bed - that's the starting point. I'm trying to do that whilst my parents are still alive so that they get into that routine of not having to do that. Mum and Dad, you know, they're 80; Dad has got a bad back. So, even though you're in a hoist, you've still got to do a bit of positioning. So I'm trying to take away that burden from them. So that's my first hurdle.

Then when they're not around any more and I want to live independently in my own house, I want to be eligible for sleepovers and that type of thing. I don't know personally whether I am eligible for that. I should be, just like everyone else. So they're the main facets of what I've sort of battled with and tried to talk to different politicians about. Most of the time they just send you a letter back saying, "We're too busy to see you," or whatever. That's frustrating, because I'm like a dog at a bone; when I get an issue, I'll write a letter until they see me and maybe that's what you've got to do. But maybe this is part of the process, that the right ears get back to the right people and they make the right changes, because right now it's just not a fair playing field. So that's pretty much it.

MS SCOTT: All right. Thank you, Gary. I don't know if you've had a chance to have a look at any bits of the reports that's been released.

MR ALLSOP (SCA): No, I've been in hospital for three weeks.

MS SCOTT: Okay, fair enough.

MR ALLSOP (SCA): The big books arrived while I was in hospital.

MS SCOTT: Okay. Well, when you get a chance, we'd welcome your comments on those. I've taken down some good notes and we've got your transcript.

MR ALLSOP (SCA): I did send you in a submission originally but - - -

MS SCOTT: Yes. Thank you.

MR ALLSOP (SCA): The other thing is that they went from the CAS scheme, which was the incontinence scheme, to a CAPS scheme, and that was designed to give us more choice for where we bought our stuff. The only problem is that since that happened the government-subsidised equipment has gone up from 10 to 25 per cent, so one condom has gone from $1.90 to $2.40. That's gone up 50 cents, you know. So that's been a monumental failure of the CAPS scheme. Again, I've complained to them and most of the time it falls on deaf ears as to what's happened. But, yes, that's another aspect of it that's actually worse now than it was.

MS SCOTT: So they increased the subsidy and the prices went up?

MR ALLSOP (SCA): No, they didn't increase the subsidy. It stayed the same.

MS SCOTT: Right.

MR ALLSOP (SCA): It was just administered differently.

MS SCOTT: Right, different name.

MR ALLSOP (SCA): It used to go to A and EP and then you bought the stuff, but now they put it in your bankcard through Medicare. So you've got the money in your bank and when you need stuff you ring up and get it, but it's gone up, and they never used to charge you for delivery and now they do. So, you know, it's not working.

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

MR ALLSOP (SCA): I appreciate you squeezing me in and thanks for listening.

MS SCOTT: That's all right. Thank you.

MS SCOTT: All right, I think we've got George and Jess next. Good afternoon.

DR TALEPOROS (YDAS): Good afternoon.

MS SCOTT: Would you like to state your name for the record and the organisation you're representing, and we've assigned 30 minutes for your presentation. Thank you very much for accommodating the change to allow Gary to speak. So over to you.

DR TALEPOROS (YDAS): My name is George Taleporos. I'm the manager of the Youth Disability Advocacy Service, which is a statewide advocacy service for young people with disabilities between 12 and 24 years of age.

MS EVANS (YDAS): My name is Jess Evans and I'm a member of the steering committee for the Youth Disability Advocacy Service.

DR TALEPOROS (YDAS): It's also worth noting that we will inject our own points of view as well and our own experience as people that live with disabilities. We wholeheartedly welcome the recommendation by the Productivity Commission for the introduction of a National Disability Insurance Scheme, or NDIS. I'd like to first put forward some things that we feel we want to strongly support in terms of the recommendations, and later we will do some feedback around some things that we think could be considered to improve it or we thought that might be helpful.

MS SCOTT: Thank you.

DR TALEPOROS (YDAS): We also want to add that we will be putting in a formal submission when we've had more time to do so.

MS SCOTT: Thank you.

DR TALEPOROS (YDAS): So the first recommendation that we wanted to support was 7.5, that the entitlement to reasonable supports is enshrined in legislation. Further to this we think that the right to self-direct the supports should also be included in the legislation, as it has been in the UK with the direct payments act. We might take this in turn, so Jess.

MS EVANS (YDAS): So recommendation 6.1, that people eligible for funding under the NDIS can choose the level of control that they have over their funding, including the option for direct payments that strongly supports the range of options provided under this recommendation for maximising choice. We also support recommendations 6.2 and 6.3 and how they describe the implementation of self-directed funding. We believe that these recommendations strike a fair and reasonable balance between flexibility and accountability and community expectations about the reasonable use of public funds.

DR TALEPOROS (YDAS): We strongly support recommendation 6.4, that people have the option to employ their own support workers and exercise more control over their lives, and have a stronger say on how the supports are implemented and who provides their support. Directly employing support workers will not be everybody's choice but we believe that it is an important option that has been trialled successfully in Victoria.

MS EVANS (YDAS): Recommendation 6.10 is essential to ensure that people remain eligible for necessary social security benefits and are not forced to pay tax on their direct payments.

DR TALEPOROS (YDAS): Recommendation 6.6 we also support. It's important because without the necessary support and information the number of people undertaking self-directed approaches will be limited. We need more information, planning and peer support groups to assist people to make choices and take more control. Overall, the key principle here is that the NDIS should include an investment in information provision and programs that empower people with disabilities to have more control over their lives.

MS EVANS (YDAS): Chapter 4.6 describes an innovative approach to disability housing. The recommendation that people eligible for this kind of accommodation can cash out the cost of providing this combination, so that they can have more choice and flexibility about where they live, is strongly supported by YDAS. If this recommendation is implemented it will allow more people to move out of group homes and have more control about where and with whom they live. This will allow them to be more connected with informal supports and with their communities. It will also increase employment opportunities and quality of life for people needing accommodation support. Furthermore, it will enable young people with disabilities to have greater choice about their housing and it is likely to support them to move into more independent living arrangements earlier in life.

DR TALEPOROS (YDAS): We strongly support, as is said in the report, that the NDIS should not be means-tested nor include any asset tests.

MS EVANS (YDAS): Chapter 4.22 says that the NDIS should consider the need and cost of taxi transport as part of the assessment. In response to the Commission's requests for guidance on what would be reasonable, it is recommended that the assessment considers the amount of travel that the individual requires to undertake vocational and recreational activities - - -

DR TALEPOROS (YDAS): "And other", I should have said, sorry.

MS EVANS (YDAS): Sorry, and other activities of their choosing, and the budget line in the individual support package be developed according to this. A 40-kilometre per day cap would be reasonable. This would be in addition to the subsidy provided by the taxi directorate.

DR TALEPOROS (YDAS): We would also like to provide the following feedback about other sections of the report.

MS EVANS (YDAS): Page 23 of the overview document says that some people have disabilities so severe that they could not realistically ever work. YDAS believes that all young people with disabilities have the potential to engage in meaningful employment if the right supports are put in place. We also believe that the NDIS provides an opportunity for many more people with disabilities to enter employment by covering the additional costs that people with disabilities experience when trying to participate in the labour market; for example, transport costs, work based disability support, training, additional personal care needs. YDAS strongly recommends the funding of work-related supports to reduce the current barriers and disincentives to employment currently experienced by people with disabilities.

DR TALEPOROS (YDAS): 4.1 describes the range of supports that will be funded. YDAS believes it is important to be flexible and innovative with regard to the kinds of supports that will be funded under the scheme. In the Victorian model of self-directed support, people with disabilities can decide for themselves what kind of support is most appropriate for the goal and outcomes that they are wishing to receive. For example, if the person experiences chronic pain as a result of their disability, they may find a certain form of massage is the best treatment for them and therefore funding for this should be available under the scheme.

MS EVANS (YDAS): Chapter 5.8 discusses how assessments should take into account informal supports, as a vital issue that is missing here is the importance of considering the person with a disability's preference for formal or informal supports. Any assessment must consider this and recognise that some people with disabilities undergoing assessment may be happy to continue receiving informal support from family members, but others may wish to become independent from their families and not rely on them for their support.

DR TALEPOROS (YDAS): Chapter 5.9 says that the assessor should determine the suitability of self-directed funding. YDAS believes that everyone should have the right to undertake self-directed approaches and that the decision should be up to the person and, if appropriate, their family. Some people may require additional supports to take on self-directed funding, and the assessment should consider what these supports might look like if a person chooses to do so.

MS SCOTT: George, are you happy to take a question as we go?

DR TALEPOROS (YDAS): Yes.

MS SCOTT: Just one about the suitability of people being able to look after their funding package.

DR TALEPOROS (YDAS): Yes.

MS SCOTT: The self-directed arrangement, where someone might receive a package of $20,000 or $7000 or - - -

DR TALEPOROS (YDAS): $300,000.

MS SCOTT: - - - a very substantial amount of money - $300,000? All right, so a very substantial package. We're cognisant that there will be some people - not everyone is born an angel - where it may not be suitable for them to look after a package. They might not have the requisite skills, or they might have had problems with fraud or bankruptcy in the past, or they might be under a lot of pressure to spend the money in ways that are inappropriate for their long-term care; they may have a drug addiction or alcohol addiction.

You've got this blanket view that everybody should be entitled to it. Could you respond about what you think is the appropriate arrangement where someone does have a background of fraud or drug or alcohol abuse, and how you think that would affect the viability, the sustainability and acceptability of the scheme if everyone had the right to manage their money?

DR TALEPOROS (YDAS): Jess wanted to say something.

MS EVANS (YDAS): Yes, I'd like to respond to that one.

MS SCOTT: Okay, sorry, yes.

MS EVANS (YDAS): I guess my feeling is that, firstly, the number of people with disabilities in that situation strikes me as being potentially not very high, but the other response I'd like to make is that in that situation there would be a second party who would assist the person with the disability to make sure that they were using their package correctly. Furthermore, with any government handouts - not to use that awful word - there are checks and balances and measures in place to make sure that people are not defrauding the system. We mentioned the UK in our submission, where there are quite a high rate of people directly employing their staff, and actually the incidence of abusing that is relatively low as well.

DR TALEPOROS (YDAS): I might add that I understand where you're coming from, Commissioner, in terms of your concerns that some people might not be suitable because they may, for one reason or another, not have the skills. I think it's the responsibility of the NDIA to put in place the necessary information, support, training, opportunities to build people's skills up to get to the point where they can do that if they so choose. I think if the assessment is done fairly - the person who will be most harmed by not using the funds appropriately will be the person with the disability themselves, and they have a right to make that mistake and learn from that lesson. I also think that the charter of human rights would say that your disability or the kinds of impairment that you have should not limit your rights and your right to take on that opportunity.

MS SCOTT: Thank you for the answer.

DR TALEPOROS (YDAS): Where were we? Assessment?

MS SCOTT: The last one you mentioned was 5.9, I think.

DR TALEPOROS (YDAS): Okay. Assessment should also consider the realistic and lawful implementation of supports - and I want to emphasise this because I think the current system fails here. For example, an assessment may reveal that a person only requires one hour of assistance in the morning. However, under the relevant award there must be a minimum three-hour shift. Also, it may be very difficult to get the staff member to work for one hour. If a person is only funded for one hour, there will be a funding shortfall that will need to be addressed to implement that support. Another example is a situation where a person may need assistance every hour for a task that only takes 15 minutes. The assessment would be misguided if it calculated all of the 15-minute assistance intervals and did not recognise that this person, in reality, would need 24-hour support.

MS EVANS (YDAS): We believe that the final report should include reference to the importance of advocacy for people with disabilities, and that advocacy should sit outside of the NDIS and be for people with disabilities - sorry, and be funded separately from individual support packages. The reason for this is that people may need advocacy in their dealings with the NDIS. Advocacy agencies need to have the capacity to take on systemic issues separate to individual client work, and advocacy services need to provide advocacy to people who fall outside of the individualised scope of the NDIS.

DR TALEPOROS (YDAS): We also believe that Victoria has done a lot of work in developing the kind of model that you've described in your report, and that

Victoria would be a sensible place to start with the rollout of the NDIS because direct payments have already been implemented as a choice for people who receive disability funding in this state.

MS SCOTT: Just on that, George, yesterday we had some people in Hobart who suggested Tasmania would be an excellent place to start.

DR TALEPOROS (YDAS): ….

MS SCOTT: So I'm just anticipating that we'll probably hear, as we go round, that there are lots of places - which just suggests that there's a certain enthusiasm and, obviously, a high level of need. So I was listening, I've taken notes, so thank you.

DR TALEPOROS (YDAS): ….

MS SCOTT: ….

DR TALEPOROS (YDAS): Can Jess say a few more things?

MS SCOTT: Yes, please.

MS EVANS (YDAS): I just wanted to add, as an anecdote, what an NDIS would mean for me personally. I guess the report sets out very well the need for more hours - which equals less reliance on family members - and that's been articulated by lots of people. I guess flexibility, though, is the real key for me. Basically, I thought about a typical day in the life of me, and essentially I have uni classes, I have times where I'm socialising, I have times where I'm doing theatre rehearsals, obviously I have transport to and from uni or whatever, I obviously have the standard meals and stuff throughout the day, and then I have some needs intermittently overnight, and of course the theory is that I do go out once in a while and have fun - shock horror!

So I think that really what we said about - my needs on paper look like not very much, but just the way that a usual day pans out really means that I need 24-hour support. That needs to be flexible so that it can include notetaking while I'm in class and meals and medications and stuff. Basically, this has come out of, I suppose, an experience where because I didn't have enough hours, and because I didn't have flexible supports, I was - and am still - in a situation where at university I have to take preventative medication sometimes just so that my notetaker, who isn't allowed to give it to me, doesn't have to - because I don't think that it's fair to say that any of my needs are life-threatening, but that medication nonetheless needs to be given when it's required.

I guess, just around the issues of transport and housing that we raised already, I would like to envisage my life as having quite flexible options there, too, so that I wouldn't want to be solely reliant on a car. I would envisage using some taxis and some public transport, but to do that I would either need more care hours, because public transport is a bit dodgy at the moment, which unfortunately is outside the scope of the NDIS, or I would need funds, which the NDIS does provide, to subsidise taxis or a van for me to use.

I guess housing: I've sort of thought about obviously the fact that I don't want to end up in a CIU or a nursing home as some people have ended up; that I would never want to live on my own, but that I would like to live with others, possibly in a rental-type situation. I've always said that I wouldn't move out with my friends because I wouldn't want to kill them by the end of it, but that's another story. You know, I think there is that goal of living independently from my parents but still feeling connected to the community somehow and, hopefully, fingers crossed, a partner eventually. I think that's all I've got.

MS SCOTT: Thank you very much. John, do you have any questions for George or Jess?

MR WALSH: It's about your second-last dot point, guys, the one about if you need help 15 minutes in every hour or even five minutes every hour and that's equivalent to a 24-hour support place. Do you think there are flexible options which mean that support can be given without having someone effectively being with you on a paid basis 24 hours a day?

DR TALEPOROS (YDAS): No.

MR WALSH: You don't?

DR TALEPOROS (YDAS): Not at the moment, and I don't suppose that they exist. Do you have something - - -

MS EVANS (YDAS): Can I respond?

DR TALEPOROS (YDAS): You just wanted to say something?

MS EVANS (YDAS): Well, I did. I suppose my feeling is that if my notetakers at uni were allowed to give me food, drink, medication and all that then, yes, that would be fine. I wouldn't necessarily have to have a carer there. With that, you're talking about legislation which governs education, which is a different department. I think that if you are aiming to have people not with 24-hour care, you have to consult with other departments and see if that can be provided some other way, which is done in the UK to some degree with employment stuff.

DR TALEPOROS (YDAS): John, did you have an idea in mind?

MR WALSH: Really, we're looking for innovation in this scheme, I think, so if you do provide a more comprehensive submission, I wouldn't be constrained by what existing legislation looks like. How would you build this from the ground up, I guess, is what we'd be interested in?

DR TALEPOROS (YDAS): Yes. I guess our reference to the clinician is not to - that with the assessments that come into play, that they are not set up in such a way where a person is left without the support that they need because it is done with that kind of mathematical time and motion type model that means that people are not adequately funded when they end up having a package that can't be translated into the support that they need on the ground. We've seen this happen a lot under the current system, so that people who need half an hour of support in the morning, for example, simply can't get that shift covered and can't also live the life that they choose because the assessment is done very narrowly and very mathematically. I was a little bit concerned with the part of the report that sort of added up one plus one equals two, when that's not how things often play out on the ground.

An issue that we haven't spoken about in what we've written so far, but I think that needs to definitely have a lot more work, is the issue around workforce and how hard it is to get people to work in the industry and to get the right people in the industry, when the shifts are often so small, and the pay conditions aren't very good. So we can have the best NDIS in the world in terms of what people are entitled to, but if there aren't people willing to work those shifts, then it doesn't result in good outcomes for people.

MS EVANS (YDAS): Can I add to that?

MS SCOTT: Yes, please, Jess.

MS EVANS (YDAS): I think that's one advantage of direct payments or, at the very least, having a flexible system. I've experienced this thing where some carers are not actually allowed to work unless they meet certain guidelines, and I think that that is a big deterrent for staff, whereas I've noticed that, when I directly employ carers, I can literally choose people, I can interview them like in a formal situation but that they can come from anywhere. Then we can work out shifts, and how often and all the rest of it, that are mutually acceptable.

MS SCOTT: Yes.

DR TALEPOROS (YDAS): And being able to, for example, use direct payments to employ your neighbour or someone that might not necessarily have a particular certificate in disability is very important for people who choose to do that because that will mean that they can have their disabilities covered, that will mean that there will be more flexibility in calling on people spontaneously, heaven forbid, and get that support when they need it.

MS SCOTT: I was just thinking, John, on the boundary issue, about Jess's assistant; that a notetaker can't provide you with a drink or - - -

MS EVANS (YDAS): They can provide me drinks - - -

MS SCOTT: They can provide you with drinks?

MS EVANS (YDAS): Yes.

MS SCOTT: I'll have to check my notes then. I'll cross that one out. I think you said they can't provide you with medicine. What about - - -

MS EVANS (YDAS): Certainly not medication and not - - -

MS SCOTT: What about food?

MS EVANS (YDAS): Not food and not toileting.

DR TALEPOROS (YDAS): Can I explain why that is?

MS SCOTT: By all means. I guessed it was because, as you said earlier, the Education Department was providing it rather than the Victorian Human Services Department.

MS EVANS (YDAS): Yes.

DR TALEPOROS (YDAS): That's right.

MS SCOTT: I was thinking, John, that if - - -

DR TALEPOROS (YDAS): Isn't it George? Are you talking to me?

MS SCOTT: No, I was just going to talk to John.

DR TALEPOROS (YDAS): Sorry.

MS SCOTT: John, the Associate Commissioner. John, I was thinking that maybe the protocol arrangements could over time address this issue of these acute boundary problems, where you could actually have rational people suggesting that there might be a more accommodating approach.

MR WALSH: Yes, I think so, Patricia.

MS SCOTT: Okay. George and Jess, anything else you want to tell us?

MS EVANS (YDAS): I suppose I just have one point which wasn't exactly covered in our formal submission.

MS SCOTT: Yes.

MS EVANS (YDAS): I really liked the fact that the report mentioned supports to self-develop ISPs and all the rest of it, which was sort of touched on, but I guess the crucial thing is that those supports then don't come out of the package itself, as we find with things like case managers in the current system.

MS SCOTT: Okay.

DR TALEPOROS (YDAS): I just wanted to ask a question if that's all right.

MS SCOTT: You may ask. I can't promise we'll answer.

DR TALEPOROS (YDAS): I was just interested in how the Commission saw the place of advocacy for people with disabilities, because - I don't know, I thought I read every word of the report, but I might have missed it. It doesn't mention advocacy at all.

MS SCOTT: Well, there you go: it does.

DR TALEPOROS (YDAS): It does? So there you go.

MS SCOTT: Yes. In the draft we have that down as one of the functions of the disability service organisation so - - -

DR TALEPOROS (YDAS): That's the problem.

MS SCOTT: - - - they'd be in your corner if you wish to have one, working on ensuring that you got the package and the supports you considered you required, so that's where we actually did have the advocacy role.

DR TALEPOROS (YDAS): So are you saying that it would be provided by disability service?

MR WALSH: Not disability services - a new group of organisations that we're calling disability support organisations.

DR TALEPOROS (YDAS): Okay.

MR WALSH: That would sit between disability service providers and those people with disabilities who chose to use them.

DR TALEPOROS (YDAS): Okay. As long as the advocacy is independent and not tied with any disability service organisation.

MR WALSH: Yes. No that's - - -

MS SCOTT: No.

DR TALEPOROS (YDAS): So you might want to tweak the language there, because I think it's very important that you distinguish independent advocacy from disability service provision, because normally we're fighting with services. We don't want it to be the ones who funded us.

MS SCOTT: Okay, all right.

DR TALEPOROS (YDAS): Does that make sense?

MS SCOTT: Yes, I understood that. That's good.

DR TALEPOROS (YDAS): Okay.

MS SCOTT: John, do you have any further questions for George or Jess?

MR WALSH: Thanks, guys.

MS SCOTT: Thank you.

DR TALEPOROS (YDAS): Thanks, John; thanks, Patricia.

MS SCOTT: All right, thank you.

MR WALSH: Thanks, George; thanks, Jess.

MS SCOTT: I now invite Jenny Willis to come forward. John, you're back on the screen, so that's good. We can see you now. Just for your information, John, Jenny has provided me with a folder of material here, which I guess at some stage you're going to refer to, or maybe not. But anyway, I've got some extra material here, John, that you haven't seen yet.

MR WALSH: Okay, thanks, Patricia.

MS WILLIS: I did submit it as an email originally.

MS SCOTT: Yes, fine. But anyway, thank you for that.

MS WILLIS: No problems.

MS SCOTT: All right. Jenny, you're representing yourself, I think?

MS WILLIS: Yes, that's correct, and Daniel - my son, Daniel.

MS SCOTT: Maybe representing Daniel as well?

MS WILLIS: Yes.

MS SCOTT: Yes? All right. I might let you start. We've set aside 20 minutes, so see how you go.

MS WILLIS: Yes, that's fine. I was made aware of this Commission on Friday, so I haven't had a great time to look at the report, other than different sections that Belinda referenced for me, or referred me to, when I stated my concerns. I guess I have a couple of concerns that I'm hoping will be addressed, the first one being inappropriate use of overnight respite accommodation that is placing children at extreme risk. The second one, the lack of after-school care for disabled children that disadvantages families.

In looking at both of these points, the inappropriate use of overnight respite accommodation: respite houses are currently being used to house on a permanent basis children who have been surrendered to DHS, often who have violent and aggressive behaviours. Placing them permanently in these or long-term accommodation in the respite system raises some issues that place severely disabled and more vulnerable children like Daniel at extreme risk, and I will give you an example of that to follow. It reduces the availability and access of respite for other families that use the houses by reducing the beds that are available. Currently in the area we live in there are around 96 families trying to avail five or six beds, and over a monthly period that's not a great percentage of availability. When you've reduced one of those beds by a permanent resident, it's a lot taken out of the system. It also increases the pressure and stress on the house staff attempting to keep the children safe.

I've submitted to you in a PowerPoint presentation some rather graphic photographs of an attack that was inflicted on Daniel back on 22 November, where he was bitten on the arms, the legs and the head by an aggressive child who's been living at the centre since September last year. I wasn't aware of her being there until after this attack took place. The bites to Daniel's legs and so on where she's broken skin on him were actually inflicted through clothing, so they were quite hefty bites, and you can see that it's not just one occasional bite here and there. It's multiple bites to the arms, the legs and the head. Daniel is 16 years of age going on two. He's non-verbal. He can't do things for himself. Some of the wounds that he has on his hands are defensive, but he couldn't make it known to the carers that he was being attacked. There were two carers on duty at the time.

MS SCOTT: In a house of how many people?

MS WILLIS: In a house - of residents? There were five or six children there.

MS SCOTT: Yes.

MS WILLIS: And there were two carers. One of them was getting dinner ready, and the other one had to go to the toilet.

MS SCOTT: Yes.

MS WILLIS: A fact of life. But in saying that, it was then brought to my attention that this girl had been living at the house because her parents had to give her up, and the responses from DHS have been - respite is now all things to all people. That's what they're trying to be, in having these permanent residents there for an extended period of time. It appears that the children I've seen go through that respite centre in particular have all been at a stage of sort of falling through the cracks. They're around the 16 to 18 years of age, just prior to falling into adult respite or adult accommodation. So there's a period of time where there's really no place for these kids to go.

I don't particularly hold the carers responsible as much as the system, and the failure within the system to protect people like Daniel, the vulnerable ones, the ones who can't protect themselves, and you expect when you send your child to respite that they're going to a safe environment. This is not the first time he's had injury in these sorts of situations: there have been aggressive kids there before.

MS SCOTT: I mean, obviously it's a very sustained attack. What would you suggest is the way to remedy this? You've explained that there were two staff to five or six clients. That staff ratio may or may not - - -

MS WILLIS: It may well have been four or five. I'm not sure.

MS SCOTT: No, that's fine, I understand, but have you thought about what is the remedy to - - -

MS WILLIS: I'm suggesting that the remedy is that there should be an alternate form of accommodation available to these children that are released to DHS - you know, surrendered to DHS; that they should not be put into a respite system. I'm sure that other parents don't know she's there. I cannot, as a mother, send him back to that centre until she's moved on.

MS SCOTT: Do you have any alternatives to that centre?

MS WILLIS: The alternatives DHS sent me - I've submitted the emails as well at the back but they were day respite, outings and things like this where there might be respite for three or four hours. They weren't overnight respite, which is what we were getting. My husband passed away 18 months ago, so it's just me with Daniel. I don't have family support, it's just me with Daniel, so I haven't had respite since November.

I guess what I'm saying is, as I said, I cannot put Daniel back in that system. DHS's attitude is, "We're stuck with the system, we have no answer for this" - or this is the response I felt I was getting and discussions I have had - "We are stuck with the system, there's no place for these kids to go, and until something is done to remedy this, this is going to continue." They're quite happy for me to put my hand up and make a noise because they feel they can't do anything about it because they have to work within the system.

In saying that, I also suggested to them that while this girl - I'm aware that she lives in another area and she goes to school, so she lives - I'll say - in the […] area. The house is in [a different suburb]. She goes to school towards […], yet she's living at [a different suburb]. Would there be a possibility of once a month or once a fortnight for her to be moved to a different respite centre for two nights so Daniel could have respite - or we could have respite? But they are not prepared to move her because of the disruption it would cause her. So once again Daniel becomes the victim because we have been told if we want overnight respite we have to go to another respite centre.

MS SCOTT: Jenny, have you been able to, or do you want to, get an individualised support package for Daniel?

MS WILLIS: I don't even know what that entails.

MS SCOTT: Okay, I just saw reference to it in one of the emails.

MS WILLIS: Let me say that since all of those discussions I have had a DHS worker come out and talk to me about getting advocacy and things like that. So that has finally happened this last month.

MS SCOTT: Right.

MS WILLIS: Up until then I had this laundry list where they suggested Daniel have psychological assessment because he did react to being attacked, and he went on an outing with a group the next day and they paired him up with a young lady and he was terrified of her. But they should well be aware, if they know their clients, with his condition he is not able to be assessed. He doesn't respond. So I felt I was being given a laundry list of things they had to do to go through their procedures to say they have covered all bases.

Last week I went and had a look at another respite centre, again just to go through the motions, but that respite centre is quite a distance from our house, whereas the respite centre he currently goes to is three minutes from school and the bus drops him off at school. Again, as I said, we are the ones that are secondary - a victim a second time with this. Nothing has happened and Daniel is not the issue. It's the needs of the girl that's taken priority. I understand she has a situation but, you know, he's as much at need and we are as much at need of respite.

MS SCOTT: Yes, I understand that.

MS WILLIS: So I'm suggesting that she's in the wrong place.

MS SCOTT: Yes, got it. John, do you have any questions for Jenny?

MR WALSH: No, I don't, Jenny. Thank you for coming in and telling us, and I understand what you're saying. I don't have any questions. I think it's an issue we understand and hopefully the scheme would support those - - -

MS WILLIS: I understand it's not an isolated incident and that you'd be aware of incidents like this.

MS SCOTT: Yes.

MS WILLIS: Just quickly, if I can just mention that as a sole carer - the second point I mentioned is the lack of after-school care for disabled children. Last year I managed to beg and plead a local after-school centre to let Daniel stay. This year they've decided he's way too old to be around five-year-olds and I understand that, although all he does is sit and listen to his music. But there is a great big hole there for kids over 12 with disabilities. I could have a very well paid job - I write training programs - but most of the organisation in the corporates I work for want you in the office to service their clients, so I need care from 3 o'clock in the afternoon until 6 o'clock and I just can't get it.

I've been offered three hours a week, which sort of doesn't really help the situation. At the moment I've had to give work away, which places a burden on the community because that's where we're going to have to head. Once my funding runs out, I'm going to have to still provide, so I'm going to have to look at ways of supporting us. But as far as offering support and care systems for the disabled and families of the disabled, I think there's a big gap there as well. If there's something there that you know of, I'd be really happy to hear about it but I haven't been able to find anything.

MS SCOTT: All right, thank you very much and thank you for coming along today.

MS WILLIS: Thank you.

MS SCOTT: Okay. Thanks, Daniel. Okay, John?

MR WALSH: Yes, thank you.

MS SCOTT: I now invite Ken Young and James Sweeney to come forward, please. Good afternoon.

MR YOUNG (IA): Good afternoon.

MS SCOTT: Could you identify yourself for the transcript, please, and we've assigned 30 minutes to your presentation.

MR YOUNG (IA): Thank you very much. My name is Ken Young. I'm the community research and policy officer for Interact Australia.

MR SWEENEY (IA): And I'm Jim Sweeney. I'm the manager of disability services for Interact in the eastern region.

MS SCOTT: Thank you.

MR YOUNG (IA): Our general submission covers a range of activities identified in the report, but first of all we would like to comment on chapter 3: who is the NDIS for? We actually thought in the tier 2 the idea of bringing forward a single umbrella of the NDIS to create information and referral pathways is an excellent recommendation. However, the complexities of identifying and mapping that we point to - well, even within regions and within municipalities - there is great complexity and great difference in the services that are provided and the accessibility of different services. We would urge the NDIS to take a very nuanced approach to the mapping that reflects the strengths and weaknesses or absence of service provision so that there is a feedback of quality mechanism in the data so there's no biases and so that the information is most accurately captured.

In the tier 3, creating the category of 3B for intellectual disability is something which we support. We think that the discussion around the function that people had would have excluded many of our clients from the system. We have some concerns. In chapter 4 the draft report talks about the provision of mainstream services and that there is a risk of cost-shifting or that mainstream services are not able to necessarily fully meet the needs of disabled people. However, an area which we're most concerned about is comorbidity with mental health issues for people with intellectual disabilities. We're aware of quite a number of our clients who would be clinically depressed but the workers don't have the capacity to identify that. Some of their behaviours and support for families are not able to be picked up on.

So in saying that there is a need for mainstream services, it may well end up being to help parents and families access things like, say, beyondblue and various other services, and also helping those service providers to understand the needs of people with intellectual disability, which is quite a significant issue for a range of people with intellectual disabilities, and we believe that the current system isn't working for them. But by excluding mainstream services, it could also be a disadvantage as well.

MS SCOTT: Okay. Thank you.

MR WALSH: I've just got a question, Ken. You said a few minutes ago that it would exclude quite a number of your clients. You didn't say what sort of clients they would be.

MR YOUNG (IA): They would be clients who would be difficult to assess. They have behaviours of concern. They can sometimes act out in an aggressive and sometimes violent way and getting them appropriately assessed with mental health issues presents difficulties.

MR WALSH: So they may be people with a mental illness. That's the group you're talking about?

MR YOUNG (IA): No, comorbidity: people with an intellectual disability and also mental health issues.

MS SCOTT: Just to clarify: the diagnosis of an intellectual disability is clear. What's not always clear or always treated or always appreciated is the fact that they have a comorbidity of mental illness.

MR YOUNG (IA): Correct.

MS SCOTT: Okay, I've got that.

MR YOUNG (IA): Correct. John, does that answer your question?

MR WALSH: It does, except just to clarify that a clear diagnosis of intellectual disability will get them into tier 3.

MR YOUNG (IA): Yes. Okay.

MS SCOTT: Good point, John.

MR YOUNG (IA): Good point. In the area of services for homeless people - this is an area which we've been working in - we believe that the accommodation and support system, particularly in the SAP services, underestimates and doesn't actually effectively count the number of people with intellectual disabilities who are in the homeless system. We provide a range of pre and post release services for prisoners exiting Port Phillip Prison here and also the Queensland prison system. Invariably, they're going initially into the SAP services, but there are also massive problems with them being supported in the SAP system. We believe that there is a useful role for NDIS to actually raise the capacity of the service system so that they are better able to address the needs of people with intellectual disabilities within the mainstream systems.

MS SCOTT: John and I have discussed this issue from time to time, so I wouldn't mind spending a bit of time on this, Ken.

MR YOUNG (IA): Sure.

MS SCOTT: Could you talk a little bit about the services that your organisation offers, the deficiencies that you see and, I guess, in each instance why the mainstream service, better directed, couldn't provide the service. Why do you think it has to be an NDIS service?

MR YOUNG (IA): I'm not necessarily suggesting it needs to be an NDIS service.

MS SCOTT: Okay.

MR YOUNG (IA): But I do think that there is a capacity building within the supported accommodation sector that needs to occur, either through funding of demonstration programs, training, or some specific services for people, say, coming out of - post release. One of the major issues for post-release prisoners with an intellectual disability or other cognitive impairments - whether ABI or other things like that - is the very high level of recidivism. It becomes a revolving door. If we can intervene and provide specialist accommodation that helps them stabilise themselves, learn some life skills, gets them into a stable accommodation pattern, then that becomes a breakaway for them from the old cycle of recidivism. In terms of efficiency, it's much more effective to keep people out of prison than in prison. The cost of imprisonment is much, much more; so developing specialist services that intervene in that pre and post release.

In my appendix 1, I have included the data under the Victorian Supported Accommodation Assistance Program. There is actually very little hard data about the numbers of people who are in the homeless system. These are figures of people who have self-identified as having either intellectual disability or a learning difficulty. They have also agreed to have their status counted. So we can see in the year 2008-09 there were, in Victoria, 826 individuals who were in the SAAP service system who were identifying as having an intellectual disability or learning disability. Up to 50 per cent of them were under the age of 24. If we can work in that larger number, we can actually then help the service system to be more responsive. It's not a parallel system; it's about making the existing system more effective.

The other area which is of interest is in the ATSI community - Aboriginal and Torres Strait Islander. It's interesting to note that even in the ATSI community with disability, it's a smidgen under 8 and a half per cent - 8.42 - but their presence in the supported accommodation system is only about 6 per cent. So there's an over-representation there. The other group is women facing domestic violence. We have alluded in our submission that - we're not proposing setting up a separate system. We're actually wanting to make the system that exists more efficient, so it's about building the capacity.

What we find is that the housing and homelessness service sector very often lacks the skills and knowledge to identify and support the needs of clients with ID, and the expertise to develop a communication and engagement strategy. For example, many organisations have house rules. They're written in English, et cetera, and people just don't understand them, whereas we've got for our accommodation service - in appendix 2 I've given an example - easy English house rules. So we believe that there is an important role to actually build the capacity of the sector, not necessarily a new parallel system.

MS SCOTT: Okay. Thank you.

MR YOUNG (IA): Chapter 5, "Assessing care and support needs": we agree that there needs to be a robust process of determining who gets what. However, we are most concerned that special needs assessments have traditionally become users of rationing and also that there needs to be a capacity for timely response. In the example we have given, we have a relatively young person who has had a special needs assessment at leaving school age, at 18. Now, several years on, two years on, there are concerns about early onset dementia and to get the reassessment of his needs, which have gone up astronomically, is up to a two-year wait, isn't it, Jim?

MR SWEENEY (AI): Yes. Look, the individual concerned within the report there has certainly shown some significant behavioural changes since his last assessment, which was probably 18 months ago. We actually had a special needs assessment done for that chap last week by a DHS representative, but the advice that I've had fed back through to me is that that assessment will go through to the DSR and who knows how long it will take. In the meantime his mother is certainly in a situation where she's a single parent without the relative support mechanisms, whether it be through respite or whether it be through us providing him with one-to-one care, and I guess it's one of those issues that raises itself all too frequently.

MS SCOTT: So that's timeliness of assessment.

MR SWEENEY (AI): Correct, yes.

MR YOUNG (IA): Timeliness of assessment is key.

MS SCOTT: Yes, okay, got that. Just, Ken, on the point about rationing, we've been clear to stress in the draft report about "reasonable and necessary" and to use those phrases.

MR YOUNG (IA): Yes.

MS SCOTT: No scheme can be open-ended.

MR YOUNG (IA): No. I understand.

MS SCOTT: But I guess what you're drawing our attention to is that it can start off being about needs but later it can end up being distorted to be about rationing.

MR YOUNG (IA): Yes.

MS SCOTT: Okay, I've got that. Sorry, did I interrupt you, James?

MR SWEENEY (AI): No, that's fine.

MR YOUNG (IA): Sure, any system has to meet the needs and it can't explode out, but it does need to have a capacity to be able to respond - - -

MS SCOTT: In a prompt way.

MR YOUNG (IA): - - - in a timely way.

MS SCOTT: Yes, got that.

MR SWEENEY (AI): I would like to add also, we've got an ageing population of people that we service and we've also got a high percentage of people that are ex-queue clients, participants. They haven't had an assessment done for a very long time and I guess, through that ageing process, their current assessment is probably not reflective of where they're at, and going through that bureaucratic procedural type of mechanism and the waiting times around the DSR and stuff like that makes the whole situation problematic.

MS SCOTT: Okay, gotcha. Thank you.

MR YOUNG (IA): Around the workforce issues, chapter 13, we do have some concerns. We fully support recommendation 3.1. However, in 3.2 we are concerned that it will place vulnerable people at risk. We have quite a robust whole-of-life approach to people's police checks. I think the case cited - you know, somebody 40 years ago will have spent convictions. We already take a very broad view of that and I would argue that most of the sector does. However, we do believe, whilst a police check is a point in time, it is certainly an important tool. On page 13.26, we're concerned at the assertion that:

> ... most employees need relatively simple formal qualifications, if any.

All of our staff in the day services all have some qualification and we see that as an important aspect of duty of care.

MS SCOTT: You will recall George and Jess's statements. I don't know if you were here for their presentation?

MR YOUNG (IA): Jim was, yes.

MS SCOTT: It's just that they made the remark that for the type of care they're sometimes after, they don't want qualifications to stand in the way of being able to recruit who they want, so I guess, Ken, could this be a horses for courses type arrangement, where in some circumstances you want very qualified staff and people with accreditation and in other cases people may not need that?

MR YOUNG (IA): That may well be the case, but it would depend also on meeting the needs of an individual person; for example, if they needed say PEG feeding, colostomy bags. There are a range of skills which have to be met and even if it was in some sort of informal care, we'd still want people to have the capacity to, say, do a PEG feed or something like that.

MS SCOTT: That requirements need to suit the circumstances: you didn't think that theme came through clearly enough on these pages?

MR YOUNG (IA): No, I didn't think so. I just really wanted to bring that as an issue that we do see. In general terms I suppose, because of the very nature of our client group being highly complex and having multiple needs, we're really caught. And again it's also a bit what Jim was talking about: some of our clients are deteriorating and you need to have skilled people to be able to observe and watch what's going on and reflect on it and then change the practice. It's not that everybody in the sector needs to be qualified, but I would argue that people who are doing special services would need to attain that.

MS SCOTT: Okay. Well, we can have a look at the drafting. Thank you for that.

MR YOUNG (IA): Thank you.

MR SWEENEY (AI): Can I just add, with our particular cohort of individuals that we service, of which we've got about 200, the majority of our people are SNA-assessed as being high and very high, so we have a particularly complex group, and I guess through our recruiting processes, that reflection around getting people that have got formal qualifications, whether it be certificate IV or a degree, is something we have as a high priority, as well as experience and as well as their personality or the merits of the individual.

MS SCOTT: Attitude and - yes.

MR SWEENEY (AI): The attitude, yes. Thank you. And I guess through our recruiting process too - and we do see people that come to us that don't necessarily have formal qualifications. We'll assist them along the journey of actually getting that. But I think it really is reflected by our complex client group as to their qualifications.

MS SCOTT: Okay. Thanks. Thank you very much, gentlemen. John, do you have any questions for Ken and James?

MR WALSH: I don't, thanks.

MS SCOTT: Thank you very much. Thank you for a very well-documented presentation. I'm pleased say that it's now afternoon tea time, so we might resume at 3.15, please, promptly. Just before you go, can I have an indication if there's anyone who does wish to make a quick comment this afternoon at 5 o'clock, because I might be able to squeeze you in earlier. I made the offer early in the day. Anyone who has been sitting here and did want to make a comment? All right. Well, we might talk just during the session. Thank you. So, 3.15.

MS SCOTT: Good afternoon. I call to the table Melissa Noonan. Nice to see you again, Melissa.

MS NOONAN (L4L): Yes, you too. Thank you.

MS SCOTT: I thought we met each other in Sydney.

MS NOONAN (L4L): We did.

MS SCOTT: There you go.

MS NOONAN (L4L): I didn't make the last one in Melbourne, so I flew to Sydney.

MS SCOTT: All right. Melissa, we've got 20 minutes assigned to your presentation and I'm going to ask you at least several questions about some of the questions we had, at the end of the overview, about artificial limbs, prostheses and so on. So let's see how you go.

MS NOONAN (L4L): Great. Thank you. I'd also like to, on behalf of our members and key stakeholders, thank the Commission for developing such a concise and detailed draft, and we're grateful to have the amputees included in there or even to be looked at. So thank you very much for that. For us, we've got a number of questions as well so that we can put in some additional information - if that's all right?

MS SCOTT: Sure.

MS NOONAN (L4L): I'll refer to the section of the draft "Information Request", chapter 4. You considered that artificial limbs would be included in the NDIS and you're seeking feedback with respect to the desirability and practicality of this. We agree that artificial limbs should be a part of the NDIS, but would like additional information, I guess, from you, that you would like us to provide you with, if possible, thanks, and what level of detail, obviously.

MS SCOTT: All right. Look, we've had - John, you're going to help me here - lots of debates internally about boundary lines between things.

MS NOONAN (L4L): Sure.

MS SCOTT: Because if anything becomes too big it becomes clearly unaffordable and unviable and we need to be clear about boundary lines. So sometimes we've used general headings like Aids and Appliances - which we're taking in the broad sense, to have a broad meaning - and other times we've gone down to be quite specific.

An argument has been suggested that prosthetics should actually be covered by the health sector because, for example, these days so many things - like knee replacements and hip replacements - are provided through the health sector - and I think you discussed at your testimony in Sydney the history of how the program that provides funding for some prosthetics items has moved from one portfolio to another and so on. So I guess there is a view that because the medical sector can be involved in some prosthetics items, you draw a line and it's all called "health". On the other hand, we were speaking to the president of the orthotic - - -

MS NOONAN (L4L): AOP, yes, Richard Dyson-Holland.

MS SCOTT: We were speaking to Richard yesterday and Richard was making the point that he thought that many items should be in the scheme and funded by the scheme. So the question is - and at the end of the day we need to have a line drawn somewhere - what items should be on the health side? I'm going to just make it easy: I think it might be hips and knee replacements. That's just off the top of my head. But what items should be on the NDIS side? We would welcome your views - and the views of anyone interested - on that dividing line.

MS NOONAN (L4L): Thank you.

MS SCOTT: At one stage somebody had suggested something as simple as "internal" and "external" and we had some discussion this morning about whether that's a workable definition. But given that you've got a very keen interest group, we'd be very keen to know exactly what those should be.

MS NOONAN (L4L): Sure. No problems, thank you. Well, that sort of clarifies my next question as well, because I wasn't sure if you also wanted us to include products that support or enhance the effectiveness of a prosthetic such as a liner, sleeve sock, et cetera, so it's probably better that we add them in the mix in the scheme of things.

MS SCOTT: Yes, I think that might be best.

MS NOONAN (L4L): Yes. The other point that I wanted to make was around obviously the early intervention. In some states, I guess the difference is that they have an interim limb program and a definitive limb program, and that's probably something that we should clarify in the submission as well, and I'm sure that probably AOPA would consider doing that too. Whereas in some states you may not meet your final prosthetist who is going to treat you until after the interim program has finished, and then when it's time for you to receive your definitive limb, then you meet - it's handed over to somebody else. So we were looking at early intervention and the benefits of patient care from that respect so that people could be with the same person or the same healthcare provider from day dot, and also in some cases have the opportunity to meet their prosthetist prior to amputation surgery, given that aside from, I guess, trauma and that sort of thing, many amputations are in some respects elective, with respect to diabetes, that sort of thing.

MS SCOTT: I think Richard was making some of the same points yesterday.

MS NOONAN (L4L): Okay.

MS SCOTT: And the issue is then not so much where the service is received from, but where the funding should come from.

MS NOONAN (L4L): Yes.

MS SCOTT: And you might want to think about that; for example, if you're suggesting to me that hospital and rehabilitation centres may well in fact be the first point of referral, but you'd like to see some continuity of services, and the question is could funding still be transferred at the appropriate point to the NDIS, even if the service provider still is the same person.

MS NOONAN (L4L): Person, or the same - yes.

MS SCOTT: So anyway, it's not my role to suggest that you might want to read Richard's testimony yesterday, but - - -

MS NOONAN (L4L): No, we'll have a look at that, thanks, Patricia. Thank you. There were two other points that I wanted to make: that in speaking with our stakeholders we would like to see a federalised funding model put into place to ensure the best possible outcomes for everybody to ensure that the system provides equality. I think as I mentioned last time, it's quite disjointed and every state in Australia operates quite differently. There's no real equitable funding model across the country and obviously a federalised system would bring that into place.

MS SCOTT: Yes.

MS NOONAN (L4L): And under the question about considering artificial limbs, there was also a notation in there about power concessions. I know that in the case of some amputees, because of reduced body surface area they have difficulty controlling their actual body temperature, so obviously make use of airconditioning systems, fans, et cetera, more than I guess other people, and therefore would like to be earmarked for that as well, as well as the obvious things like home modifications, vehicle modifications, et cetera.

MS SCOTT: Okay. Thank you. John, do you want to chip in now? Have I done justice to the prosthetics discussions that went on?

MR WALSH: I think you have, Patricia.

MS SCOTT: Of course, we didn't do it over several hours or days.

MR WALSH: I'm not sure we're any further advanced, but I've been thinking about the internal/external ones, just through the course of today, and one that struck me that probably wouldn't fit is, for example, colostomy or ileostomy bags. They're external appliances but probably are health system responsibilities I would have thought.

MS NOONAN (L4L): Yes. I guess for us the main line or the difference in the sand between an internal or an external prosthesis is that if you're having a hip or a knee replacement, and you have for example private health cover or you are on a waiting list to have surgery, chances are you will still get a knee or hip replacement valued at something like $23,000 to $30,000, whereas external componentry is benchmarked in many cases in many states - for a below-knee, off the top of my head I think it was about $4000 to $5000, or an above-knee about $6000 to $7000, which is a huge disparity in funding for those two things, when in actual fact in a lot of cases they're providing, obviously, mobility for a person. Unfortunately there's no area where external prosthetics can tap into any other funding stream.

MS SCOTT: One of the presenters this morning pointed to maybe we could use the definition out of one of the IS 900 classification arrangements. It was Natasha, who presented that this morning - Natasha Layton and Peter Wilcocks - and Peter had a special modern arrangement which assists him to walk and government funding only covers a small proportion of the total cost. He was a survivor of polio. Natasha thought that there might be a definition within existing Australian standards that we could use as well, so we'll have to try and do some more work on this area, but we would certainly appreciate whatever you can offer, because we are finding this quite problematic. Is there anything else you'd like to tell us?

MS NOONAN (L4L): No. I just wanted to clarify a few things so that when we come back to you we can hopefully give you - - -

MS SCOTT: I just want to check: on the desirability line you've got, I guess, need, and you've got deficiency of existing arrangements, and you've got variations between the states. The second part of the question was on the practicalities - this is this dividing line - but also goes to the service delivery, the fact that if all the services are actually in the rehab, does that work? And now we've discussed the potential variation between funding and service provision.

MS NOONAN (L4L):   Yes.

MS SCOTT: But if there are other practical things that you could focus on, we welcome that. Thank you very much.

MS NOONAN (L4L):   Thank you.

MS SCOTT: Okay, John?

MR WALSH: Thanks, Melissa.

MS NOONAN (L4L):   Thank you. Thanks, John.

MS SCOTT: Now we're going to hear from Geraldine Moore. Welcome, Geraldine.

MS MOORE (ADHDCVI): Thank you very much, Patricia.

MS SCOTT: We've got 20 minutes for your presentation, so thank you for providing notes in advance to us. Over to you.

MS MOORE (ADHDCVI): My name is Geraldine Moore and I'm secretary of the Attention Deficit Hyperactivity Disorder Coalition of Victoria Inc. I became involved with ADHD support because I had two boys who are now grown-up young men and they both had ADHD, and we had a pretty difficult time years ago. In fact I ended up writing a book about it, and more latterly I was involved with the National Health and Medical Research Council when they recently revised the national guidelines on attention deficit hyperactivity disorder. Those guidelines are now available on their web site, although they're still in draft form awaiting final endorsement.

We will take the opportunity to put in a formal submission to the Productivity Commission, but I'd just like to say a little bit about ADHD because it is often referred to as the hidden handicap. When you see people who appear to be able-bodied but don't appear to perform commensurate with their IQ and their opportunities that they have in life, it's hard to always understand why that is.

Now, ADHD is a common condition and it's been defined in the Diagnostic and Statistical Manual of Mental Disorders number IV as a pattern of inattention and/or hyperactivity impulsivity symptoms that persist for at least six months, to a degree that is maladaptive and inconsistent with developmental level. I hope that's clear, because some people say, "Well, all kids are like that." Maybe, but not to that degree and not at that age.

The other really important thing is the question of impairment. The DSM-IV goes on to say there must be some impairment from symptoms that is present in two or more settings - eg, at school or work and at home - and there must be clear evidence of significant impairment in social, school or work functioning.

One of the paediatricians who did a lot to raise public awareness of ADHD was Dr Christopher Green, who was the head of the child development unit of the big children's hospital in Sydney. He was very fond of saying, "A problem is only a problem when it's a problem." It doesn't sound like it makes a lot of sense, but what it meant is we're not just talking about attendancy or an eccentricity, but we're talking about something that has a major detrimental effect on your life. So it's not just some unimportant kind of deficit; it's actually quite a major one.

Not every person with ADHD has all the symptoms, they're not always equally severe and the level of impairment can vary between individuals. It can also change over the course of your lifetime. Some disappear with age, some reduce with age, and some persist. So there are a lot of people who are diagnosed in childhood and they go on to have the same sorts of problems, or slightly different but still largely the same problems, in adulthood.

There are also a lot of associated problems - what the clinicians call comorbidities - and the common ones are learning difficulties and anxiety and depression, but there are others as well - speech problems, coordination problems - and there's a crossover with autism as well.

The long-term outcomes for individuals with ADHD are wideranging. Individuals are at an increased risk of a number of adverse outcomes and this is not always recognised. The first common adverse outcome that goes along with ADHD is academic underachievement, so they do poorly at school, especially if you measure their IQ. You usually find that there's a big gap between what their IQ predicts and their performance. The second one is difficulties with interpersonal relationships and self-esteem. This often has serious consequences for the individual.

The flow-on effects of ADHD often have significant effects on families, schools, workplaces and the community. In school-age children you'll find that, compared with non-ADHD children, they have poorer results in reading, spelling, maths, they more often repeat classes and more often require remediation and tutoring. In their friendships, there are often fewer friendships. Those there are often not sustained. There are poor relationships, often, with parents and siblings. This can be, at least in part, because inattention affects the perception of social cues. The hyperactive and impulsive behaviour that's a hallmark of ADHD often results in social rejection by peers. These children have a lot more accidents and injuries, and this is also related to impulsive behaviour. One other thing that has only fairly recently been identified is that there's a bigger risk of obesity.

With adults and adolescents, compared to their non-ADHD peers, fewer of them go on to higher education, more drop out of courses and have lower grades. When they get to work, more frequent dismissals, more frequent changes of employment and more frequent problems about performance.

Driving is another area. Compared to non-ADHD peers, ADHD adults have more driving accidents, traffic infringement notices and they more often lose their licence. Substance abuse: they start earlier, and there's an increased use of alcohol, tobacco and other drugs compared with non-ADHD peers.

Again, obesity: a risk factor. Relationships: more trouble keeping friends, more marital breakdowns. Sexual activity: more likely to take risks. 19 to 25-year-olds in the general population, 4 per cent of that age group have children - and these are American statistics. 38 per cent of ADHD in that age group have children. Sexually transmitted diseases: four times the probability. Crime in Australia and elsewhere: markedly more ADHD people are placed on community orders in juvenile justice centres and end up in prisons. So it's a big problem not only for the person themselves but also for society.

The internal experience of ADHD is really quite a distressing one. There's a much greater incidence of anxiety, mood disorders, eating disorders and poor self-esteem.

How is ADHD managed? At the start, individuals with ADHD and their families and carers should be provided with information and education about ADHD and its impact and the advantages and disadvantages of potential treatment strategies. The most usual treatment approach is what's called multimodal therapy. This usually includes psychosocial management strategies, educational interventions - such as they might need a bit of tutoring or remedial help - and in some cases medication, and there is a range of other therapies that are added in as required for the individual; maybe speech therapy or occupational therapy, dietary management. There's quite a range. From this, an individualised management plan is supposed to be drawn up in collaboration with the person and with their parents or carers, and teachers if they are children.

MS SCOTT: Geraldine, we are coming up to the last four or five minutes. We are particularly keen to hear about your views on the draft report if you've had a chance to have a look at it.

MS MOORE (ADHDCVI):   Yes.

MS SCOTT: Would you like to move to item 6 in particular in your list of topics?

MS MOORE (ADHDCVI):   6? Okay.

MS SCOTT: The list that I've got here has got how it's going to relate to the disability scheme.

MS MOORE (ADHDCVI):   In terms of the NDIS disability scheme, the ADHD Coalition welcomes, in general, the notion of a national disability insurance scheme. One of the things that we particularly like about it is the fact that we hope that it will be based on a social model of disability so that we're not only looking at disability in terms of physical disability and sensory deficits but also looking at a wider model that includes the social interactions that a person experiences as a result of the disability.

We're particularly pleased that there is a preventative aim in the National Disability Insurance Scheme because we think that's very, very important. We're pleased also that there is an emphasis on respite. Our ADHD families have terrible problems with physical and mental exhaustion, financial strain and particularly with community stigma and they really need respite. They need financial help to pay for the costs of diagnostic tests and for treatment plans, which typically are very expensive, involving counselling, tutoring, medication and other therapies.

There is a period that is particularly burdensome for families and that is when a child is first diagnosed and first put on a treatment plan, because there are a whole lot of very big expenses at once. So it would be really helpful if at that particular time there could be some financial assistance. We believe that it would be consistent with the National Disability Insurance Scheme for special assistance to be available to families particularly at that time, and for the dissemination of information throughout the community to counteract the stigma about attention deficit hyperactivity disorder, which is based on lack of knowledge. I'll leave it there.

MS SCOTT: Thank you very much. John, do you have any questions for Geraldine?

MR WALSH: Yes. Thanks very much, Geraldine. I've got a couple of questions. You mentioned a lot of statistics about increased risk of various things happening for people with ADHD. Any reference or - - -

MS MOORE (ADHDCVI): Yes, the references are in the notes that I supplied by email yesterday and I also have them in the handouts that I have here today. The main one is the National Health and Medical Research Council revised guidelines 2009. It's a very long document. It's available on the Internet on the NHMRC web site.

MS SCOTT: Is it still in draft form?

MS MOORE (ADHDCVI): Yes. It was completed in 2009 but they're still waiting for some issue in America to be resolved regarding one of the scientists before they finally endorse it. But it has been endorsed certainly by the Royal Australasian College of Physicians and I'm sure that in time it will be endorsed by the National Health and Medical Research Council as well.

MR WALSH: I've only just seen your paper today. Does that document give a spectrum of severity and support needs? What I find interesting is the prevalence of ADHD that provides a support need commensurate with what we're planning to recommend for the NDIS. I guess my question is, there's a spectrum of effects of ADHD.

MS MOORE (ADHDCVI):   Yes, certainly.

MR WALSH: Very mild through to very severe.

MS MOORE (ADHDCVI):   Yes, indeed, and that was my little comment before about a problem is only a problem when it's a problem. Unless the impairment is significant then they don't really warrant a diagnosis. It might be just colloquially given to them by people, but a proper clinical diagnosis really has to wait for clear evidence of significant impairment.

MR WALSH: I'm hoping in this document you've given us that there's some prevalence data in that.

MS MOORE (ADHDCVI):   Yes.

MR WALSH: Linked to that prevalence data, what sort of support needs are recommended for those severe cases?

MS MOORE (ADHDCVI):   Well, they talk about respite, they talk about dealing with stigma and they talk about the multimodal therapies and individualised management plans that are devised for each case.

MR WALSH: Okay, and there's some detail about that in that document?

MS MOORE (ADHDCVI):   There's a lot of detail. It's a very long document. It took two years of some of the best brains in Australia from paediatrics, psychiatry, psychology, special education and general practice to put that document together. So it is very detailed and it's done to the highest standards of scientific validity.

MR WALSH: Okay, thank you. That's great.

MS SCOTT: I have no questions for you, Geraldine, so thank you for coming along today and thank you for your material.

MS MOORE (ADHDCVI):   If anyone wants any copies of the materials that I have, I'm very happy to give them out. Thank you.

MS SCOTT: Okay. Thank you.

MS SCOTT: I now call to the table Nerida and Michael from the Transformation Management Services. We're a little bit early. I might jump ahead. So is Martin Fry here? Okay, let's not worry because, Chris, you're here and you volunteered that you're going to speak to us this afternoon.

MR HARVEY (GDV): I'll be substitute.

MS SCOTT: Yes, that's right. There you go. It means that we might - well, I imagine you've got five or 10 minutes. Is that how much time you need?

MR HARVEY (GDV): Yes.

MS SCOTT: All right. Can you identify yourself and the organisation you represent, please?

MR HARVEY (GDV): Yes, certainly. My name is Chris Harvey. I'm chief operating officer for Guide Dogs Victoria and I'd like to thank the Commission for the opportunity of speaking today, particularly without notice, so thank you very much. Just by way of background, we're still wading our way through your hefty document - congratulations on getting it out - so my comments today should be taken as preliminary. Guide dog associations are state based and it is our plan to put a combined formal paper to you before the submissions close, so be anticipating of that, please.

Guide Dogs, just by way of background, provides orientation and mobility services to vision-impaired and blind members of our community. In the preliminary reading of the paperwork we see some opportunities and we see some threats and concerns, and I'd just like to summarise those today, and please interject if I've misinterpreted or missed critical points from the documents in my reading today.

First, in terms of opportunities, similar to someone who presented earlier this afternoon, we applaud the idea of a tier 2 service giving advice to those that are impacted by disability. Our clients report to us that it is a difficult maze to find your way through currently and we see that a combined one-shop, if you like, advice centre offers the opportunity to provide clarity and comprehensive advice where in some quarters that's lacking currently. So we see that as a potential advantage to us.

Further, and again similar to a previous speaker today, we like the concept of an early intervention category in tier 3 and it is our position that orientation and mobility programs have the aim of assisting our clients with mobility-centred independence and therefore connectedness with the community. We see that those services would fall within the early intervention category and we also understand that they have high economic return and it's likely that we'll be providing some statistics from an Access Economics report of a few years ago to support our position in our formal submission. I'm not sure whether the Commission has seen that report but we'll be quoting from it.

So there's some words of support for the Commission, a few words of feedback, and one of the things that we spent a bit of time thinking about already is what could be some of the unintended consequences of the scheme? There are two in particular that I wish to raise today. The first relates to quality. We have a passion for the quality of service we provide and we have a concern that, in a situation where there is a significant increase in the funds available for service provision, there may be new players in the market that perhaps don't share our passion for quality and may have different drivers in terms of establishing what they do. So we would like to advocate very strongly to the Commission that a set of standards, both for service delivery and outcome quality - we see that as essential, either within the scheme or aligned with the scheme, and certainly I'm speaking on behalf of Guide Dogs Victoria. We stand ready to provide input to what those standards might look like and, as a minimum, be engaged in that process should the Commission choose to take that action.

Secondly, Commissioner, you mentioned the word "boundaries" before. That's very important for us because we foresee that perhaps not all of our services will fall within the NDIS scheme. With our organisation the majority of funding is by donation and so one of the fears we have is that there may be an unintended consequence on our operation - which I'll label "donor complacency" - whereby members of the community may feel that they're contributing to the provision of disability services through their insurance premium or tax - whatever it's finally labelled - and therefore they may choose to place any donation elsewhere in that circumstance.

We recognise that fundraising is our responsibility, but where the Commission can assist us is by working with us to be clear on what is in and what is not in the scheme. Then we anticipate that we'll have to take some deep breaths and go and work with our donor community to emphasise that we actually still need them and that there are certain services that we offer that are not included in the scheme, and please would they kindly consider helping us out into the future. So that's important from our perspective.

A concern that we have is the interface between an NDIS scheme and the aged care system. We believe that that interface needs to be very clearly defined. At this point in time we are a little bit dubious as to whether the aged care system would provide the equivalent level of support and our view is that our clients have a right to equivalent support, noting that many of our clients come to us either just before or, indeed, after the pension age, so might be suffering from age-related vision impairment which could be degenerating around about the same time as the cut-off period that's proposed through the NDIS. So we would like some clarity and certainty around the overlap, if you like, or the way the two schemes will operate. Thank you very much.

MS SCOTT: Thank you, Chris. I might draw your attention to recommendation 8.3, which is about a quality framework for disability providers, and you may or may not find words of comfort there.

MR HARVEY (GDV):   Yes.

MR WALSH: I think just on that one, Chris, how you measure a quality outcome for your particular service would be useful.

MR HARVEY (GDV):   Yes. We are in the process of finalising an outcome standard for a guide dog team, we're also in the process of defining outcome standards for orientation mobility services and we have a tool which we've designed that looks at the effectiveness of our service provision.

MR WALSH: If they're available, that would be useful to have a look at.

MR HARVEY (GDV):   Okay. Thank you.

MS SCOTT: All right, I've got no further questions for Chris. John, are you happy to wrap up there?

MR WALSH: Yes, thanks, Chris.

MR HARVEY (GDV):   Thank you.

MS SCOTT: Thank you for coming along.

MS SCOTT: I think Nerida and Michael are here. We're operating a tight ship. So I know you're not due to be here till 4 o'clock, but we're just keeping it moving along.

MS WALLACE (TMS): No, that's all right. We're at your disposal.

MS SCOTT: Thank you. Just to remind you that we are making a recording for public transcript purposes, so it would be handy if you didn't defame anyone.

MR HALL (TMS): So any defamations are out, yes.

MS SCOTT: And John is coming through on Skype from Sydney. He's the Associate Commissioner for this inquiry.

MR WALSH: Hello.

MS WALLACE (TMS): Hello.

MS SCOTT: For the transcript purposes could you state your full name and identify the organisation you're representing and we'll take it from there.

MS WALLACE (TMS): My name is Nerida Wallace. I'm a principal of Transformation Management Services, which is a legal consulting firm based in Melbourne which specialises in the design of dispute resolution systems for compensation schemes. This is my partner - - -

MR HALL (TMS): Michael Hall, who can speak. Yes, I'm a principal of Transformation Management Services as well, and I've been co-author of most of the reports that Nerida has done around Australia in the last 20 years.

MS SCOTT: Okay. Thank you.

MS WALLACE (TMS): Our consulting firm began in - is it useful for me to give you a copy of this?

MS SCOTT: Yes, I was just checking whether I actually had a copy of it, but I don't know if I have.

MS WALLACE (TMS): No, I apologise.

MR HALL (TMS): I see that Skype has fallen over again.

MS SCOTT: Yes.

MR HALL (TMS): I'm sorry, we prepared a PowerPoint presentation but it's not on today, so we'll share, if you can look at that.

MS SCOTT: All right, that's fine.

MR HALL (TMS): And we'll send you the copies through.

MS WALLACE (TMS): We'll certainly send this through.

MS SCOTT: Good. Thank you very much. John is still available on the phone, so don't worry if the Skype comes in and out.

MR HALL (TMS): Yes, okay.

MS SCOTT: John, we might give up on Skype this afternoon. It's just a little irritating the way it drops in and out from time to time. But anyway, it's free and we don't get a lot of free things. So off you go.

MS WALLACE (TMS): All right. We've had nearly two decades in dispute system design and in fact have presented to the Industry Commission and the Productivity Commission on its previous inquiries into compensation frameworks, specifically workers compensation. We've probably designed and re-reviewed now - which is a bit sad - most of the schemes in Australia and New Zealand in workers compensation. We're currently reviewing the CARS system in New South Wales for the Motor Accidents Authority CTP Scheme - which I won't talk about today because we're still in the process of reviewing that - and we've developed, in that period of time, a best-practice framework for designing these systems. We just thought we'd give you the elements of that today, together with some observations on your proposals for the NDIS.

MS SCOTT: Thank you.

MR HALL (TMS): Our work has also covered a lot of other jurisdictions, including courts ombudsman systems in Australia and New Zealand, so it's a wider background.

MS SCOTT: All right. Thank you.

MS WALLACE (TMS): Our design framework looks at disputes as a population of interactions and transactions. We take the view that disputes are not fixed items as a lot of courts seem to look at them. They're actually human interactions, they can be managed, and interventions at certain times will change what happens in those disputes.

So when we look at well-run dispute systems, they will firstly have - and I think it's actually the third-last slide here, but we say that if you've got a well-run scheme with a lot of education material and communication with the public about what the benefits are, you will have fewer disputes. If we look at Queensland, for instance, in workers comp they've had the same sorts of benefit structures for a very long time, so they don't have too many disputes. Singapore is another good example. So you can get rid of a lot of disputes just through that sort of education.

MR HALL (TMS):   The education can go to things like production of videos and material to explain how the dispute system works or the first steps to avoid having a litigious dispute.

MS WALLACE (TMS):   The initial event, which is the claims decision, is our next area. The quality of the claims decision can actively determine whether the matter goes to dispute or not. Some of our early research showed that if a claims officer contacted a claimant personally rather than sent them a letter, the chances of that matter going into dispute reduced from one in three to one in four. That was some early research we did for Comcare. I haven't got the Comcare chart here, but we did our research for them I think in 1996. By 2000 their disputation rate had turned around quite significantly. That's written up in their annual report. Part of that was changing the way the claims officers made their decisions.

The next area is representatives, and we say that you should have advocates, non-legal paralegals, involved at that level. You should have a lot of resources in the community to assist people to negotiate directly. The first review point is probably where you've made recommendations, but you have to have review officers. Again, what we're saying is that if these systems are working really well, proportions of disputes will be resolved at each of these steps, because clearly the longer these things go on, the more expensive, and in poorly run schemes you see they won't be resolving at the front end, they will be resolving at the back end.

MR HALL (TMS):   So in our examination of different schemes across Australia, we've mapped the resolution of cases at different points and been able to reflect on the different ways the schemes operate and the different ways they intervene, the different pressures that there are on different components to move stuff through to court or to avoid court, and look at the breakdown of cases and how they're resolved. So optimally they're mostly resolved at the education level, then at the first representative level, and a decreasing proportion successively until, in an ideal scheme, the proportion of cases that go through to review on the law is very, very small indeed.

MS WALLACE (TMS): After review we have facilitation, which is often a mediation process, but it needs to be a place where people can be heard about what's happened to them. Again, this is very important to stop these matters going further. When we're looking at the drivers for these systems - when we did the major review in 1995 of all the workers compensation schemes we found that there was sort of a five-year turnover. These schemes go for a while and they would come under serious criticism and then they would basically be changed, and it was a movement, putting them back into court or moving them away from court.

MS SCOTT: How much did you attribute that to the features of the scheme versus the electoral cycle?

MS WALLACE (TMS): We ended up - that's a very good question.

MR HALL (TMS): There's a proportion of that. I think we came to the conclusion that there are two opportunities for governments to change schemes: either in the dying stages of a government cycle or in the first flush of the next government cycle. Apart from that they don't want the noise of a dispute management system and they will do whatever they can to keep the noise down. That being said, we had a lot of opportunities to observe schemes changing in the meantime, and that gets to the next level of subtlety, where you have pressures from different stakeholder groups, and that's what we'll get into because we see your scheme as being slightly different.

MS SCOTT: We haven't suggested in our process a mediation stage. Are there some state-of-the-art mediation arrangements that you can point to, that you could suggest, Nerida, Michael?

MS WALLACE (TMS): Probably the conciliation service in Victoria here. Because they have been operating - they have beaten the electoral cycle. I think we set it up in 1990 and it's still going in pretty well the same form, and there are elements of the scheme design that go to sustainability and longevity.

MS SCOTT: So I just want to check that. Because we've looked at existing schemes, and you are often making references to workers comp and workers comp is largely outside our remit, is a conciliation service in Victoria - is that how it operates within a TAC setting, in a WorkSafe setting? Where does it operate in?

MS WALLACE (TMS): The closest in the CTP environment is in New South Wales with the car system.

MS SCOTT: So you're not aware of any mediation-type service operating within a - - -

MS WALLACE (TMS): A serious injury?

MS SCOTT: A serious injury arrangement.

MS WALLACE (TMS): Not that I've seen, but you will get mediation in the courts, but they're usually for lump sum rather than pension situations.

MS SCOTT: Do you think there's a reason why mediation isn't a feature of existing arrangements?

MS WALLACE (TMS): I think I can say my observation of the CTP schemes in Australia is that they're old-style compensation systems because they're mostly fault based rather than no-fault based.

MS SCOTT: Well, we've got three that are no-fault based.

MS WALLACE (TMS): Yes, but compared with workers comp they haven't taken the next step into the no-fault pension review improved claims management, non-adversarial. The adversarial systems are the ones that are usually lump sums. Research shows that where you've got lump sums you will attract legal activity. Where you've got legal activity you will have an adversarial approach, and mediation in courts really works when the parties have got all the information they need about the case and then you can get a result.

MS SCOTT: Thank you. That's clear.

MS WALLACE (TMS): So when we're looking at these schemes we look at those sorts of economic drivers. We know that you've got to say, "Well, when does a dispute resolve?" We know they resolve when all the information is collected, as I've said; when people have been heard; when they understand what they want from that dispute; and when they've given the outcomes that will meet their requirements or their needs, together with an understanding of the benefits and the technical detail of the benefit that applies to their case.

The other issue is accountability and control. In these dispute systems we find that, as I said, they lurch from a court environment where the compensation scheme has no control over the costs associated with those, so scheme administrators typically respond by setting up what are called administratively based systems. So we've got a lot of those here in Australia, and they then in turn become legalised and then the costs blow out again.

What we're trying to do is to say, "How independent should these sorts of administrative processes be?" and in many conversations with many people who run these, they will say, "We need more independence. We need more status. We need more authority." In schemes where they're given more status and more independence, they're still coming under criticism, so we have to look to see why that is happening.

One of the things we think is very important is that they should have control over their resources and they should have a governance structure that enables them to speak directly to the minister and they're not part of a department, they're independent, and certainly in Victoria the CTP tax system has actually done that. They've gone through a process of understanding that internal review officers has not worked for them; they need to be more independent. And New Zealand is currently looking at a similar change. So I think you've got to get this balance right.

MR WALSH: Nerida, just on the TAC one, I think one of the issues we've had is that there's an overlying common law availability that compromises the quality of dispute resolution.

MS WALLACE (TMS):   Yes, and I think that's part of the problem we have, actually. It's just adversarial. Where you've got lump sums and you've got an adversarial environment, it's very difficult to get some of these things right.

MR WALSH: But how do you construct this scheme, conciliation or mediation, and protect it from becoming legalised, I guess - is the challenge that we have.

MR HALL (TMS):   The next couple of pages will tell.

MS WALLACE (TMS):   You're ahead of it. You've got to look at the legal cost as a market and you've got to look at the legal industry as a market, and one of the things we used to say to the scheme administrator was, "Needs before rights." If you help people very early on, then fewer cases will get into disputation. If you give them other types of services, paralegal services, to help them through these processes, you will have fewer of the extreme negotiations.

As an economist no doubt will tell you - and I'm not an economist, but I know you've got plenty of economists - if you create cost incentives to bring the parties' preparation work and exchange of information forward so these cases are resolved earlier in the process rather than later, then you will reduce disputation and the exacerbation of disputation that causes legal costs.

But you've also got to have the carrot and stick. You've also got to have the stick. So you've got to have cost consequences and probably the dispute management protocols that no doubt you've been told about in TAC and in some of the other schemes are an excellent approach to that. I should say that in Australia we're way ahead on what are called in the civil procedure literature "pre-litigation protocols", and that is a major advantage in some of these schemes and probably one of the reasons TAC does keep some control over its legal costs.

You've actually got to go through these schemes very carefully. You've got to actually map them and at each stage look at the incentives and disincentives, and if you understand there's an underlying pattern of behaviour going on and how disputes are resolved, get all the information in, make sure it's relevant, hear the parties, find out what they want and deliver it to them, you'll get rid of a lot of these disputes.

Some classic examples: I remember looking at Western Australia. They had in one case 52 medical reports. Well, that was obviously excessive. So there are things you can do to cut the numbers of medical reports. Have a medical arbiter system: two reports only and a third medical expert who determines which one is the correct one. There are things you can do like that.

MR HALL (TMS): Can I give a couple of other examples there?

MS SCOTT: Yes.

MR HALL (TMS): Treating doctors' reports can be taken as the definitive medical report, and that's been done as an experiment in some jurisdictions. You can also have the medical reports, instead of them being isolated, being shown to the next medical practitioner. That tends to drive them together rather than driving them apart.

MS SCOTT: I have to say that doesn't sit very readily with other advice we've received, Michael, because we're trying to apply a social model to this issue and doctors quite reasonably take a medical model to the issue - well, many doctors take a medical model to the issue. They may not see the capabilities of an individual. They may well see lots of conditions. So the advice we've received from a large number of organisations and individuals is that we wouldn't use the treating doctor's report as the fundamental "pass go" on an assessment because they're not actually designed for the same purpose. If we're talking about the bigger scheme, the NDIS, it's about capability and impairment rather than condition per se.

MR HALL (TMS): I'll clarify that. It's not a treating doctor's report as in just the treating doctor. It's a treating doctor who has been registered to actually look at those particular injuries, so they would be part of a group who would be approved for that sort of purpose.

MS WALLACE (TMS): But they're also not determinative. They're the starting point. The schemes that do better have those as starting points, otherwise you'd start off with one doctor at one extreme, one specialist at one extreme, another, and then away we go. But there's reams of information we could give you on that. Probably the point is that we find that compulsory referral to mediation should be the default position. A lot of people will say, and have said in the past, that you can only get an outcome in mediation if people volunteer to be involved in that. That's not the case. Mediation is a process that takes people through various steps and, at the end of it, they will always say, "We should have done that before." But it is a structured process to get a result, to get an outcome.

But you will get disputes that have to be screened and streamed direct to other types of processes, so you have to have a very good, strong registry, strong front, a door gatekeeper for the registry to send those cases off, and that comes from years of experience and lots of debate about what the criteria should be for those. But where you've got that set-up, it works extremely well.

I think I've said to you that the resources should be with that dispute service and the ones that don't work so well are where the departments have the budget and there's always a fight for budget.

MR WALSH: Nerida, I realise it's hard to do this without some more understanding of the scheme, but some indicative ideas of what an appropriate budget might be for a workers comp scheme of a certain size would be useful, I think.

MS WALLACE (TMS): I could possibly get that for you, because we've been looking at unit costs for the resolution of disputes. I might see if I can get that and come back to you.

MR HALL (TMS): And you could multiply that by what you would expect would be a disputation rate.

MR WALSH: Yes. We'd have to make that assumption. Right.

MS WALLACE (TMS): Yes.

MS SCOTT: We've got a few. It goes to that in the report in a chapter on some of the governance arrangements. I'm just conscious that we've probably got about 10 minutes before we finish.

MS WALLACE (TMS): Okay. We're almost there.

MR HALL (TMS): Proper resourcing.

MS WALLACE (TMS): Yes, proper resourcing.

MR HALL (TMS): Page 10.

MS WALLACE (TMS): Page 10. There's a bit of a tension going on here. These dispute resolution systems can be a great advantage to these schemes, so one of the other reasons the administrators bring them back into the administrative umbrella is because they get a lot of information from them. They're good safety valves. The unusual cases are dealt with very quickly and well. They provide guidance to claims officers in decision-making, they provide standards on how those cases should be decided and they very quickly sort out the legislative framework so that they control the entry to the dispute system just by giving a lot of feedback to the rest of the people within the scheme.

The decision-making in terms of disputes is also made within the context of the compensation scheme. One of the big complaints about courts is that they have got no idea of what's going on with the liability or the impact of some of the precedent decisions, so if you've got this sort of dispute system mechanism sitting there, it's providing a huge source of information to all the claims officers who are making decisions and all the other aspects of that scheme. So that's the big advantage. Some schemes we've looked at don't take that advantage and so their systems are sort of sitting off, not getting the support perhaps that they should get. Probably our major point is to say that these systems are always surrounded, they're always subject to criticism, and you have to always defend them.

MR HALL (TMS): They exist in a dynamic tension with stakeholders with different reasons for doing the actions or different drivers - economic, behavioural, or interest - and simply altering the scheme in one area won't necessarily solve a problem; it could cause another problem in another area. Blocking lawyers from having access to disputation mechanisms in New South Wales, I think, for hearing-related causes, made them take up cudgels and send audiological vans out to industrial sites and offer incentives to people to name their co-workers at industrial places so they could get more people on to litigate.

MS WALLACE (TMS): So what to do about that? You must have a strong focus on consistency. The major criticism that precipitates change when the government does change is a criticism of bias and a criticism of inconsistency, so consistency, credibility, constant feedback, triaging cases to the right forum, a needs before rights focus, constant claimant surveys - the 360-degree surveys are very important; user group consultation, constant user group consultation. And you need judicial credibility at the boundaries and the Workers Comp Commission in New South Wales is a good example, and in Western Australia, where they have a presiding judge over the whole dispute resolution system. There are some pros and cons to that, but you do need a judicial supervisory role.

MS SCOTT: Have you had a chance to look at some of the chapters in the report?

MS WALLACE (TMS): Yes.

MS SCOTT: So we have reference in the draft report to an office of - John, do you remember the name? Sort of like a fair-minded person to undertake the reviews.

MS WALLACE (TMS): Yes.

MS SCOTT: A statutory officer. Do you think that would meet the model you're talking about?

MS WALLACE (TMS): It's part of the model, because a statutory officer from my reading is the review officer. I think you also need to have a conciliation and mediation process, and then I'd have a judge sitting at the top of it.

MS SCOTT: Is there a reason for it to be a judge?

MS WALLACE (TMS): You just need the judicial authority and protection.

MR HALL (TMS): If you have a look at the picture that has the circle in it, the wheel, as we call, originally done in 1994, that's on page 14. It actually maps the cycle that these systems go through when they're under attack from different areas, and how they shift and change to adapt, and how that precipitates new attacks.

MS SCOTT: And having a judge overcomes the attacks?

MR HALL (TMS): In one part of the cycle, yes.

MS SCOTT: How do you instil in a judge the need for sustainability of the scheme?

MS WALLACE (TMS): The way it works in the Compensation Commission, a judge will come for three years and move back into the court, so they have a rotating process.

MS SCOTT: Yes, that's the process, but I want to know how you ensure that the judge has sustainability of the scheme at the heart of his or her consideration.

MS WALLACE (TMS): The judges usually come from that area of law, so they've been working in that area of law. You cannot tell a judge, "We need you to make decisions to keep the scheme viable." You can't do that, but you just get a judge who understands that firstly they're in a system, and that's a good start, so they can take judicial notice of whatever information is provided.

MR WALSH: Nerida, I remember in the New South Wales Workers Comp Commission - - -

MS WALLACE (TMS):   Yes.

MR WALSH: - - - set up in the early 2000s, one of the issues with that - I mean, as you say, there was a judge at the top, at the head of the Commission, and the judge only really got involved when there were appeals up to the judge. One of the issues was the acceleration of the number of those appeals, so it's a bit like in any system where there's effectively common law access, everyone wants to go to the highest right of appeal, so how do you control that snowball happening?

MS WALLACE (TMS):   I understand they've just appointed full-time decision-makers. They had sessional decision-makers, and that was part of the problem there. The sessional decision-makers were also practitioners in that particular area of law, but it was very difficult to get consistency across that group, and they've now determined to have a core of full-time people that they're training, and in the systems the decision-making point is the Achilles heel in all of these systems. You've got to get it right. I think people who have been injured deserve nothing more than full-time dedicated people, frankly, who get it right and are properly trained and resourced.

MS SCOTT: What about a person born with a disability? Would you have the same attitude there?

MS WALLACE (TMS):   Well, anybody actually.

MS SCOTT: All right. I just wanted to check, because we have to suggest two schemes. I just want to check whether you were indicating that you wanted this arrangement for both schemes.

MS WALLACE (TMS):   I think the issue here for me, when I was looking at this - and when we discussed it - was it's even more important to have a sustainable scheme, one that is not going to be subject to the winds of change and criticism, because these are going to be long-term relationships that these people are going to have with this scheme. They might be coming back into it a couple of times in the course of their lives, so having stability is very, very important.

The other reason for mediation is that mediation is very good for resolving issues when they're ongoing relationships, and I think a lot of the disputes are going to be between carers - some of the organisations you've heard from - and some of these people with disabilities. So it's not sort of a single, come in, have a workers comp claim, get better six months later. This is actually far more important to get it right, so really when we're sitting down and saying, "Well, what's the best thing we can say?" you don't want a departmentally based system that's always running off to the CEO or the secretary for funding amidst other priorities. You've got to have dedicated budgeting. You've got to have ministerial reporting, and you've got to have a judicial umbrella of some sort to give it some credibility.

MR HALL (TMS): And if the judicial umbrella is replaced every three years, and they don't become a tsar in the system whose personality is essential for its longevity, what you've got to do is try and get sustainability. That means that no single person is absolutely essential to that system, but they can be replaced by someone equivalent.

MR WALSH: Would you have legal representation at any stage of the system?

MR HALL (TMS): I think we debated that quite a lot in the car, and we thought that we see a lot of legal representation with lump sums because it's honey and it attracts people who can get money out of that system. Where you've got a long-term payment system, it's less likely to require that, but we do see that a proportion of the people coming through the system require assistance in framing their requirements, and we've seen some interesting experiments in Tasmania where they have Office of the Worker Advocate, which is a sponsored type of a system to - - -

MR WALSH: Exactly. I think some of the issues will be ideological.

MS WALLACE (TMS): Yes.

MR HALL (TMS): Yes.

MS WALLACE (TMS): But you've got to do a functional analysis. We did do some research some years ago and found that the disputes that cost less were the ones where lawyers were used initially, but if lawyers were in at the end of the process they cost far more, and were typical of high-disputation type systems. So it's a strategic use of legal skills that's important, and you've got to be careful in a pension scheme of having a legal industry where those skills exist.

MS SCOTT: We weren't suggesting a pension scheme.

MS WALLACE (TMS): No.

MS SCOTT: We're suggesting a care and support scheme.

MS WALLACE (TMS): Care and support scheme, yes.

MR WALSH: This one is going to be more about - rather than pension or lump sums, this will be about entitlements; some support entitlements. So it becomes ideological and I think potentially has a lot of the same issues as a lump sum scheme with legal representation.

MS WALLACE (TMS): Okay.

MS SCOTT: We set out two options in the draft paper. I welcome your view now or later about which of those two options on the basis of your 20 years of experience would work better. One is to have a complaints office and, as I said, an independent statutory role to determine, and the other is more along the lines of an AAT arrangement - Administrative Appeals Tribunal arrangement. I'd have to say all the people we've spoken to who operate schemes have suggested that for sustainability reasons you'd go with draft recommendation 7.2 rather than draft recommendation 7.13.

MS WALLACE (TMS): They could be right about that.

MS SCOTT: Okay.

MS WALLACE (TMS): The problem with the AAT - TAC have done some very good things with VCAT in Victoria. VCAT has some delay issues and cost issues, and TAC have done some very good work, so you would need to - yes, you could use the AAT. You could have a particular judge with list responsibility. You could do it that way. You'd need to write some things into the legislation to make sure that this list didn't get caught up with the problems of all the other lists in that organisation. Yes, you could do that.

MS SCOTT: Okay. I want to get a better sense of mediation, Thank you for the slides, but you know the advantage of PowerPoint is that you feel you've covered the topic and then when you got back to look at them later, you realise there's just six lines on a - - -

MS WALLACE (TMS): We'll bring all our reports as well.

MS SCOTT: No, I don't want to do that. I was wondering - thank you for your interest in this topic - if there's some smaller level of documentation about how you think mediation would work in this environment, I imagine you'd envisage that after the initial complaint and initial review, you'd then have mediation, and then you would have, in your mind, the judicial - I'll call them statutory, but you might call them judicial - officer then review the matter.

MS WALLACE (TMS): Yes.

MS SCOTT: Because people haven't raised the mediation role with us before I think - John, do you think this is the first time people have talked to us about mediation?

MR WALSH: It is, but it's something that I expected we'd have within the proposal that we put forward.

MS SCOTT: All right. Look, I welcome learning a bit more about mediation. If there's material you can refer to us, that would be appreciated.

MS WALLACE (TMS): Yes.

MS SCOTT: So thanks for coming along today. John, are you happy to wrap up there?

MR WALSH: Yes, but I'd welcome your submission.

MS SCOTT: Yes.

MS WALLACE (TMS): Okay. Thank you.

MS SCOTT: All right, thank you very much for coming along. That's great.

MS SCOTT: Now, on to Martin Fry, our last person presenting today. Hello, Martin. Come forward. Martin, would you like to, for the purposes of the transcript - and I have mentioned defamation before, haven't I, John? For the purposes of the transcript you might identify whether you're representing yourself or an organisation, and then we've set aside 20 minutes for your time and you can anticipate a question or two.

MR FRY: Okay. Thank you. I sent some notes to the Productivity Commission and I apologise if they arrived late yesterday. John, have you seen those yet?

MR WALSH: I've got it, Martin, thanks.

MR FRY: Okay. That starts off by saying these are my personal comments and not those of my organisation, Taylor Fry Consulting Actuaries, or any of my clients. So would you like me to go through the gist of my comments?

MS SCOTT: Yes, please.

MR FRY: My first point is to congratulate the Commission on achieving a breakthrough and addressing the provision of equitable care and support for those who have significant disabilities. It's been a long time, John, and congratulations on your part in it. The gist of my comments is aimed at the smaller of the two schemes, the NIIS scheme and, in particular, the risks and opportunities of some of the estimated costs in there. The particular topic I wanted to address was table 16.1, which had estimates of additional costs of lifetime care and support for each state and territory. I looked at the two columns "Motor vehicles" and "General injury" and I've also had a look at the 2005 PWC report on which that table was based. So I take it that the estimates are in 2004-05 values and I agree with the comments there that they only provide a guide as to the likely current costs, but they will be a useful guide.

The particular issue - there are two comments I make. The first is that under "Motor vehicles" the costs for New South Wales, Victoria and Tasmania are all shown as nil and that's based on the rationale that they're already no-fault schemes, so you don't have to prove fault; you just have to have an accident. Looking at the details of some of the schemes, they do have a number of exclusions: things like vehicles have to be registered and insured in some states. If they're accidents on private property they're not covered and off-road vehicles are often not covered in these schemes unless the people actually take the trouble of taking out an insurance policy, which I suspect is probably not often the case.

There are lots of people - you see them at the weekends, people loading up their quad bikes and dirt bikes and going off in trucks and trailers, and I suspect the vast majority of them don't even know that if they have an accident they've got no cover under a CTP scheme. Some also do not provide cover if the injured person is convicted of a serious offence like manslaughter or culpable driving. So there will be some additional costs and in my note I attempt - not very well, but attempt to put an order of magnitude to it, and it seemed to me that the incorporated nominal defendant costs in some schemes - some of the CTP schemes have an incorporated nominal defendant, so if you can't prove who is at fault and you can't sue anybody, the nominal defendant steps forward. My recollection, and John might comment on this, is that they have in the past made up somewhere in the region of 4 to 6 per cent of scheme claim numbers.

So if we took that as our benchmark - and it's a leap, but I've said if half of those claims are already covered under these no-fault schemes - that is, they're picking up the uninsured on-road vehicles but half of them are uninsured off-road vehicles - we'd be looking at something like an additional $10 million cost per annum across New South Wales, Victoria and Tasmania.

MS SCOTT: Okay, thank you.

MR WALSH: I think a nominal defendant would certainly be less than 10 per cent, Martin, so I think that's probably roughly right.

MR FRY: It's not huge but across the three schemes. That's the private vehicles that are uninsured or unregistered. The off-road vehicles seem to me to be a little bit more problematic. I make the observation in my note that all of the CTP schemes around Australia have seen quite dramatic decreases in claim frequency over the last 30 or 40 years and that's been driven by very much improved vehicle safety.

Now, what's happening in off-road vehicles seems to me to be the reverse, that we'd expect there for the claims to be getting worse because, quite by accident, dirt bikes are becoming more popular, as people become more affluent they're becoming more widespread, and I suspect that probably the reverse is happening; that the numbers of accidents - I don't have any facts to support this but I suspect that the sort of downward trend in the schemes is probably the reverse of what's happening in the off-road area. I don't have any more to contribute about that. I don't know how we'd find out how widespread accidents from those sorts of off-road vehicles are.

MS SCOTT: John, the TAC doesn't cover off-road as well as on-road? I thought they did.

MR WALSH: There are some very strange interpretations of coverage, Patricia. It's not always clear what's covered. It depends - like they might be off-road; it depends what they're driving. For example, tractors are treated differently from cars, which are treated differently from quad bikes and so on. We'd need to go through the legislation to know exactly what's covered.

MS SCOTT: All right.

MR FRY: I've actually been through the web sites of some of the schemes over the last week or so and they're remarkable opaque, John, as you know. They don't go to much trouble to explain what they don't cover.

MS SCOTT: I just think I recall some conversation about some off-road accidents, but let's take that on notice and we'll look into that. Please proceed, Martin.

MR FRY: Okay. So that was all I had to say about the motor vehicles. The other area I was going to comment on was the general injuries. I looked back at the 2005 PWC report and saw the estimates of costs for each state and territory and the basis for apportionment. I expressed it as a percentage of the estimated costs in the same report of the motor vehicles. So general injuries look like they about 40 per cent, 41 per cent of the cost of the no-fault schemes. What's proposed to happen is that those schemes will take responsibility for managing these general injury claims, so they're taking on, if you like, another 41 per cent of claims. It's proposed in the report that local government sources of revenue - that is, a surcharge on rates - be used to fund this. But the point is made that these costs estimates at 41 per cent are very uncertain. They're much more uncertain than the workers compensation or the motor vehicle claim costs.

So we've got a fairly certain pool of money from the CTP schemes with motor accidents. We're adding a substantial 41 per cent loading. That is highly uncertain. We don't know how much these general injuries will cost. So we're adding uncertainty to certainty for a start and we're funding it with - sorry, it's proposed - the Commission has proposed that it's going to be funded from local councils. The consequence of that seems to me that if the number is wrong, and it certainly will be because it's so uncertain - it may be too high or too low but it will almost certainly require some adjustment.

That process of funding presents a risk. You're going to have local councils told that they need a surcharge of so much and in the next year or two years or three years, however long it takes to emerge, they're going to be told it's wrong and there's going to a lot of bias towards changing that surcharge. I'm sure there won't be a bias if it's a reduction but there may be quite an impediment to increasing the surcharge after it's been initially announced. It seems to me there's a danger that that will simply be glossed over and the CTP schemes will make it up, make up the difference. They will find that the surcharge they're adding isn't quite enough, they will put up their rates to drivers a little bit to cover it, and so you'll have a transfer of where the funding is coming from.

MS SCOTT: What about a counterargument to that that, while the percentages are significant, 41 per cent, the actual numbers that we're talking - because we're talking about the catastrophic injury class - when you consider the very large scheme on the other side, the injury scheme numbers are quite small. Do you agree that the actual numbers are quite small?

MR FRY: Absolutely, yes.

MS SCOTT: Right, okay. So I'm not disputing your 41 per cent, but for a scheme to go from having 20 new people to having 40 new people, that's a 100 per cent increase, but still just 40 new people. In the case of rates - maybe the work we're relying on you don't feel is robust, so by all means tell us if you have doubts about it, but as a proportion of rates charged on many properties, the increase is going to be actually very small.

So you're pointing to the uncertainty factor surrounding the surcharge, for example, but if a person is paying, say, $800 in rates - I'll just use that as one example - and it goes from being $20 to $30 or even from $20 to $25, being a 25 per cent increase, in the scheme of the level of rates overall it may actually be a very small component of the annual increase. Would you like to comment on that?

MR FRY: Yes. Answering your first question about the numbers, you're absolutely right. The numbers in Victoria, I think, are 50 or 60 - John? - serious injury long-term care cases in the TAC.

MR WALSH: It's a bit more than that, but it's of that order, Martin, yes.

MR FRY: But they absorb something like 20 or 25 per cent of the scheme claim costs? Or is it even more than that, John?

MR WALSH: About 20 per cent of the cost, but I believe it's 70 per cent of the liabilities.

MR FRY: Yes. So of the annual costs, the 70 or 80 claims a year make up 20 per cent of the costs. The other tens of thousands make up the rest. So you're right. They're very small in number. The same in the Tasmanian scheme. They get about nine of these claims a year, so we're only talking about an additional four or five claims year, but each one has got an average cost of a couple of million dollars. They're big dollars involved. So you're right about the numbers.

The other observation about that is it will take some time for us to know, because the numbers are so small. You can see there's quite a lot of variability from year to year. So if you start off with the first year of operation being a low number of these claims, we might underestimate the surcharge even more. If it's a high number, you might - it will take some years for the numbers to get some sort of clarity to them.

MR WALSH: The good side of that, Martin, is I don't think we'll have to wait that long. I think because most of these claimants go to dedicated hospitals - you know, the severe spinal cord injuries and the severe brain injuries - we can do a bit of research before it starts and get some idea of what the coverage would be on an ad hoc basis. There are no questions of liability here. So what we really need to do is count the number of very severe spinal cord injuries and brain injuries who go through one of the major trauma centres, and I think we're trying to start that work as soon as possible.

MR FRY: Okay. Did your 2005 report refer to that source as one of the sources of data?

MR WALSH: We tried to. But that was done in quite a hurry; we didn't have a lot of time. But, yes, the numbers in the 2005 report were based on whatever information we could get out of the specialised spinal and brain injury units.

MR FRY: Yes. I agree with you by the way. I think you're absolutely right, that it's just a matter of counting them and it won't take very long to make - in fact you could go backwards perhaps a couple of years even and find them out.

MR WALSH: The problem is that the data is not great. The hospitals don't keep data in the way that we'd like.

MR FRY: No, I'm sure of that.

MS SCOTT: We approached the - - -

MR FRY: Sorry, there was a second question you asked me and that was on the surcharge.

MS SCOTT: Yes.

MR FRY: If the surcharge turns out to be understated by a factor of 50 per cent - which is quite plausible - it won't represent much of a change, but to the councils - if the surcharge is 0.1 per cent and it goes to 0.15, I suspect there will be an uproar. Even though it's a tiny loading, these things - I've seen it in other areas, where people get a number fixed in their head, and even though in the overall scheme of things it doesn't seem to mean very much, people get fixated about surcharges and loadings.

MS SCOTT: Thanks for that. I'm conscious that there would be any number of variations in costs affecting local councils in a year, but I understand the point you're making. What about alternatives? We approached the rates issue on the basis of efficiency of tax. It's a good tax base. We've got plenty of studies that will point to that, but obviously the most recent is the Henry tax review that points to the efficiency of that tax base. Given the variability that you see in this arrangement, is there an alternative tax arrangement or alternative revenue base that you could suggest to us?

MR FRY: The first one that leaps to mind is just leaving things, letting the numbers lie where they fall. That is, if you get the surcharge a little bit wrong and ratepayers pay a little bit too little or a little bit too much, the balance will be picked up by motorists. It seems to me there's a pretty high correlation between people who own property and people who own cars, so you won't get it too far wrong. You'll get some people who are renting who own a car who will be paying a little bit more, who wouldn't be if they were paying rates, but there's not going to be a huge injustice if you get the numbers a little bit wrong on either side - you know, people pay a little bit more on their motor vehicle or pay a little bit less on their rates or vice versa. It doesn't seem to be of earth-shattering importance.

MS SCOTT: So you think that motorists and state governments will be more tolerant on variations in comprehensive premiums than they would be about rates increases?

MR FRY: Getting back to the first point I made, the CTP schemes by and large have had big decreases in claim frequencies.

MS SCOTT: Okay, yes.

MR FRY: So rates have coming down, if not in dollar terms then in real terms. In a number of schemes the premiums haven't increased for some time, so they're in an atmosphere where things are going down, and so if they just flattened out for a year or two that wouldn't be disastrous.

MS SCOTT: No, I understand.

MR FRY: So it seems to me there's a capacity to pay there.

MS SCOTT: Yes, that's attractive.

MR FRY: Some of my CTP clients would not thank me for saying that.

MS SCOTT: That's very interesting, thank you. All right. Sorry, I interrupted your flow of thought.

MR FRY: No, I was finished.

MS SCOTT: Okay, that's good. John, any more questions for Martin?

MR WALSH: No. Thanks, Martin. I think the points you make are absolutely right. Between now and when the scheme is proposed to roll out, I think we need to do a lot more work to try and narrow down this uncertainty.

MR FRY: Yes. I guess the last thing I would say is that with loaded council rates, since it is going to be a relatively small surcharge it would be sensible to err on the side of conservatism in the initial setting of that council rate. I can see John nodding on the screen.

MR WALSH: Yes, that's what we always do, isn't it, Martin?

MR FRY: No, never, John.

MS SCOTT: All right, thank you very much for your contribution.

MR FRY: Thank you.

MS SCOTT: Yes, very good. I think that draws this day to an end, John. We've got through the list successfully. I'll adjourn the hearings and we'll resume tomorrow at 9 o'clock. So thank you very much for your attendance today.

MR WALSH: Thanks, Commissioner.

MS SCOTT: Thanks, John. Goodnight now.

AT 4.49 PM THE INQUIRY WAS ADJOURNED UNTIL
WEDNESDAY, 6 APRIL 2011