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TRANSCRIPT OF PROCEEDINGS

PRODUCTIVITY COMMISSION

DRAFT REPORT ON DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT BRISBANE ON MONDAY, 11 APRIL 2011, AT 9.01 AM

Continued from 8/4/11 in Canberra

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MS SCOTT: Good morning, everyone. My name is Patricia Scott. I'm the presiding commissioner for this public inquiry. Welcome to our hearings today. We have 14 presentations today, so we've got quite a schedule. If you'd like to see the schedule, it's available outside. Thank you for coming along today. It's very important to have public participation in this important inquiry. Are there any representatives from the media here today? No? Thank you. Our draft report has been released on 28 February. You may have seen the overview and recommendations, but there is of course a larger report available, two volumes, for those that are interested.

Today we'll be making a transcript of the presentations. That's so it can go on public record. If you wish to follow the other days of hearings - we've had hearings already in Hobart and Melbourne and Canberra - you can do so by going on to our web site. There's a small delay as the transcript is typed up and made available - and you can follow the other capital cities if you wish. Because this is a public hearing, you may want to keep that in mind when you give your presentations; the fact that information you will be providing will be read by other people, not just heard by other people here today. So all of this is available on our web site at pc.gov.au. You click on there and you go to current studies and then you follow the prompts.

You're not required under our act to give an oath. To make a presentation today you don't have to give an oath, but the act does require that you are truthful in your remarks. Of course, because other people will read your material, it may draw comment or support or criticism, but that's part of the public process. Submissions are due on comments on the report - favourable or critical, it doesn't matter, we don't mind - at the end of this month, 30 April. Our final report will be made available to the government on 31 July. The government will then release the report at a time of its choosing.

So without further ado, we'll start the hearings. The associate commissioner for these hearings and this public inquiry is John Walsh. John will be joining us by Skype at some stage during the morning. So I now welcome to the hearing Garry Burge. Garry, can you hear me?

MR BURGE: Yes, I can.

MS SCOTT: Welcome, Garry. We have assigned you 15 minutes for your opening statement and for any questions that we might have for you.

MR BURGE: That will be fine.

MS SCOTT: I understand you're not representing an organisation, but you wish to present as an individual to the inquiry. Is that correct?

MR BURGE: That's correct, yes.

MS SCOTT: Please commence your opening statement now.

MR BURGE: Okay. My name is Garry Burge, and I'm an adult with Asperger's syndrome on the autism spectrum. I was diagnosed by Dr Tony Attwood in 1998 and I'm self-funding my own advocacy. I've also just written a book called "I Want To Work - An Asperger Story" which will be available through Asperger Services Australia through their bookshop. I also have a web site, which is www.garryburge.com. I just wanted to correct that my name is spelt with two Rs instead of one.

I have 10 points I'd like to bring to the attention of the Productivity Commission, and that is, firstly, my own advocacy as an adult on the autism spectrum. I think the first thing that's most crucial and needs support is employment support - this is employment support for adults on the autism spectrum. This includes job coaches, work placement and staff development, these coming from disability employment agencies. The second requirement is accommodation support; what happens to adults once they evolve from childhood into adulthood and the parents die (audio cut-out) and there needs to be support.

Awareness of the autism spectrum in adults: as I stated before, my recent book, which is called "I Want To Work - An Asperger Story"; the increase in services for adults with autism and children; early intervention in schools; a united approach to autism for all of Australia, not just splinter organisations. There needs to be a united approach to go directly to the government in terms of, across Australia, an autism organisation.

In sort of support for my own advocacy, I'm actually going to the United Kingdom in June of this year to visit the work of Autism Works, which is an employer of adults on the autism spectrum in software testing. There's a similar project to this happening in Denmark called Specialisterne. The ninth point is the software testing. We need to get software testing in Australia to employ adults on the autism spectrum.

The final point I'm wanting to make is that the autism spectrum is a stand-alone disability. People do not see the autism spectrum in persons that have Asperger's syndrome, et cetera. There needs to be greater awareness brought into the community, canvassed across the Australian community, so that people become more aware of Asperger's syndrome. At the moment there's not a lot of awareness, and a lot of adults, including myself, are living a lot of their life in social isolation, unemployment, and just an overall ignorance and lack of understanding across the board. So these are the 10 points that I'd like to raise, and I would be more than happy to take questions from the committee regarding what I've actually presented just now.

MS SCOTT: Okay, thank you very much, Garry. Welcome, John.

MR WALSH: Hi, Patricia; hi, Garry.

MR BURGE: Hi, John.

MS SCOTT: You're coming through very well, John, here in Brisbane.

MR WALSH: Good.

MS SCOTT: Okay, Garry, could you just talk a little bit more about software testing, and maybe talk about its use in Australia versus overseas and how it would assist in terms of employment prospects.

MR BURGE: Okay. Software testing is actually getting off the ground by Thorkil Sonne. His son is on the autism spectrum. The main benefit is that software testing, from what I understand, involves rigorous testing of software that involves a mind-set for errors, so that people who are on the autism spectrum can laboriously or painstakingly test software, information technology software, so that it can be running to perfection. In Australia I do believe we need something like this to get adults into employment.

I'm actually involved with a gentleman here who works for a legal firm called Toogood Lawyers, and he is involved and very interested in getting this set-up off the ground, and I work in the University of Queensland and there's actually some support towards raising awareness of autism and I'm meeting with a lady called Sylvia Rodger, who is actually quite interested in providing the awareness. But the main thing is - their benefit to Australia - that software is going to reach the market that is going to be rigorously tested and any errors eliminated, so that when the consumer goes to buy the product they're not buying a faulty item, they're not having something that's just not working properly, et cetera.

Adults on the autism spectrum are proven to be very good in employment, when they are given the opportunity, and to be able to undertake routine tasks. Like in my own instance, I've been working in the University of Queensland library for six years now, shelving books, which involves a lot of understanding and awareness of the Library of Congress Classification order. A lot of the neurotypical people that are not on the autism spectrum find such work mundane and tedious, and there isn't really a long stay in such employment, but adults on the autism spectrum are more able to spend large amounts of time and energy in being able to ensure that any faults or difficulties or errors are overcome and rectified accordingly.

MS SCOTT: John, one more question, if that's all right with you. Garry, could you explain how the software testing assists the individual? Is it about the type of characteristics of jobs that would suit them, or is it about diagnosis, or is it about therapy? Could you just explain a little bit more what the software does?

MR BURGE: To combine all three of those, the software testing, first of all, would give an adult on the autism spectrum a sense of pride because that person would have a job. Secondly, the software testing would provide therapy, so to speak, in terms that the adults on the autism spectrum, including myself, have low self-esteem. It's very difficult in the employment process to be able to pass the job interview stage because it involves social skills, and the whole process tends to discriminate against persons on the autism spectrum because they are unable to perform well in job interviews and being able to succeed in overcoming this obstacle to enter employment.

The software testing would be something that would be rigorously tested, as I have stated before, and it would involve a very sharp focus on attention to detail. How it would benefit Australia is that the positive of employing an adult on the autism spectrum would be seen. We'd be actually providing a service and a product to the consumer that has been rigorously tested, so that any errors that may have existed, for example, are overcome by the attention to detail, mind-set for errors individual on the autism spectrum. We just need to work with the individuals on the autism spectrum to be able to capitalise and harness their skills and abilities.

MS SCOTT: Thanks for that answer. John, do you have any questions for Garry?

MR WALSH: Yes, I've got a couple. Garry, software testing: effectively the attraction of this notion is that people on the autism spectrum have an attention to detail which allows them to test software very well. That's the idea?

MR BURGE: Yes, that's correct.

MR WALSH: It can be across a whole range of software?

MR BURGE: Well, that would be the idea. I have to actually go to England in June to find out what exactly the nitty-gritty is in terms of what Autism Works are doing, but my friend and fellow adult on the autism spectrum, Chris Mitchell, is involved in this project in the United Kingdom as we speak. When I come back from the United Kingdom I hope to bring back with me information that will greatly assist those that are interested, that I'm working with, towards getting this project here. It will give them, hopefully, a greater understanding of what needs to be done.

MR WALSH: Yes, that's good. My other question is, you mentioned library work and categorisation of library items.

MR BURGE: Yes.

MR WALSH: Are you aware if there's a directory of types of employment, like those two examples, that would be most appropriate to people on the autism spectrum? There must be other types of employment.

MR BURGE: There are other types of employment, but the thing that's very difficult is the interview process. The problem is that adults on the autism spectrum don't succeed in job interviews and they need employment agencies to be able to assist them with attending job interviews. The main problem is that, when attending a job interview, the adult on the autism spectrum - and this is really sad for Australia - there is very little job support in terms of assisting the adults when they go for employment because when they go for a job interview they just don't understand the social skills required, and they're not reading the body language, and there's also the added burden of anxiety. So by the time they are going to the job interview they are obsessing too much about these things and misreading social cues.

I think there needs to be a review of the selection process, which is very difficult, as I can imagine. This is why software testing is perhaps one example of being able to get adults on the autism spectrum into employment because the focus, with that in the United Kingdom with Autism Works, is that there isn't really a selection criteria, there isn't an interview process; there's a means of actually being able to have an expression of interest for adults on the autism spectrum to apply for the position and to see how they succeed at it; that there aren't the conventional measures of actually employing persons through the normal process of the selection criteria.

This is why I actually wrote my book "I Want to Work - An Asperger Story" because even in my own situation I just find I cannot go beyond what I'm doing. I'm keen to learn and broaden my skills, but I'm held back by the interview process and also the socialisation process of employment because persons on the autism spectrum aren't really good at socialising. It's not one of our strong points. We're more focused on attention to detail and doing our job properly. If there isn't an awareness in employment, that can wrongly be misconstrued as being aloof, arrogant or not interested in socialising. This is why we really need to get awareness out there, and disability employment agencies, to provide support where necessary.

MR WALSH: Yes, I understand. Thanks, Garry.

MS SCOTT: Garry, one more question from me.

MR BURGE: Yes.

MS SCOTT: In your points - I think you mentioned in the material that you gave us just before - you talked about accommodation support.

MR BURGE: Yes.

MS SCOTT: You talked about the difficulty in people affording their own dwellings.

MR BURGE: Yes.

MS SCOTT: Could you talk about this type of accommodation support you are interested in the commission considering?

MR BURGE: Yes. I believe that the present public housing fails to support adults on the autism spectrum because the needs of housing commissions are for persons on low incomes and the disabled. I have heard stories from adults who are on the autism spectrum - the very few that are able to get into public housing - that they're not comfortable, really, in the dwellings because there happen to be other persons that may have other forms of disabilities that are not manageable. There are also medication issues with other individuals.

I think the adults on the autism spectrum need employment that's sort of segregated away from the mainstream other disability forms, so that there's more tolerance of the actual symptoms. Asperger people like myself prefer time out and things like that. I'm actually having to house-sit because it's the only way I can afford independent living. I'm really not comfortable with housing commission arrangements because I just feel that I'm not really in the same demographic as other people. I'm not really a person that has schizophrenia or a mental illness or what have you.

I understand that those people also need support, but they are not really good at being combined with people on the autism spectrum. I think there needs to be more accommodation that meets the criteria of the person on the autism spectrum, and also the fact that, as they become adults, the parents aren't always going to be around, and there needs to be support. I have three older siblings and they are not really interested in my own wellbeing. What will happen when my parents pass on? Where will I be? Those are the concerns that not only concern me but my parents, and we really need to do something about providing accommodation for adults.

MS SCOTT: All right. Thank you very much. Are you aware that the draft report floats the idea of a cashing-out of public housing subsidies or supports? Is that an idea that appeals to you, or maybe you haven't had a chance to consider it?

MR BURGE: I haven't really looked into that in detail, but what I believe needs to happen is that there needs to be some sort of subsidising or making it more possible for persons on the autism spectrum to afford their own unit. I mean, they may not want to live in public housing. They may want just an affordable unit that's comfortable and able to satisfy their requirements.

There isn't an easy solution to this but there needs to be some sort of way that there's more tolerance and flexibility in terms of providing support for adults to be able to meet the requirements of living independently - you know, units or what have you. If there's some sort of way of providing support through a body corporate, if there's some way of providing some sort of support through them, it may make it more possible and affordable for adults on the autism spectrum. It really needs to be explored further but we really have a lot of issues I think happening with adults and the future of their lives in terms of living with their parents and what happens with the inevitable, when the parents pass on.

MS SCOTT: Thank you, Garry. John, any further questions for Garry?

MR WALSH: Thanks very much, Garry.

MS SCOTT: All right, thank you for your time today.

MR BURGE: Okay.

MS SCOTT: I now welcome Lyn Raphael. Good morning, Lyn.

MS RAPHAEL: Good morning.

MS SCOTT: Welcome here to the hearings.

MS RAPHAEL: Thank you.

MS SCOTT: We've allowed 15 minutes for your opening statement and you might allow a little bit of time for questions from John and I.

MS RAPHAEL: Okay.

MS SCOTT: Please commence.

MS RAPHAEL: Thank you. I would like to applaud the comprehensive draft report and recommendations. This process has clearly galvanised people into action with a moment that is historic. I have had an increasing level of physical limitation myself over a period of 16 years and been the recipient of the gamut of care ranging from informal and paid, pilot schemes, community aged care packages, hospital care, to residential aged care, including inappropriate placement in a locked dementia unit and now more appropriate residential care.

Whilst my disability journey is but a nanocosm of the national disabled or, more aptly termed, functionally-limited population, I hope my contribution is helpful. There are four points in the draft report I would like to address. Firstly, I would like to speak to the glaring exclusion of those with a severe disability of long-lasting mental health conditions such as schizophrenia from the categories of those who would be eligible for NDIS funding in draft recommendation 3.2. For a start, the categorisation and phrase of "long-lasting mental health condition" perhaps needs to be amended to something such as "significant affective disability".

Whilst it is appreciated that chapter 3 of the information request seeks feedback on where the boundaries might lie between the mental health sector and NDIS, this severely disabled group should without question be included as an equally eligible category alongside those with significant mobility, self-care, communication or intellectual disability in tier 3 as a separate category. They are just as deserving and needing as other categories. To not do so is blatant discrimination against a group of our own and only serves to further stigmatise and marginalise people with mental or more aptly termed affective disabilities, and highlight the general ignorance about the needs of this group. Anyone with any disability or limitation knows all too well that feeling. The United Nations Declaration on the Rights of Disabled Persons does not differentiate between physical, intellectual and affective disorders.

It is well known that the mental health system per se is in crisis overdrive, with proponents of change in this area struggling with government for desperately needed funding and a system overhaul. The available community care in this area of disability is abysmal. Many of those in this disability subgroup need high-level community care and support, much of which is non-clinical. There is barely any available. They experience fractured hospital care or, by default, are relegated to homelessness, the prison sector or locked dementia units in age-inappropriate nursing homes. The stark picture of the film One Flew Over the Cuckoo's Nest is still alive but just in another guise.

I would envisage NDIS create a new category in tier 3 on a par with tier 3a and 3b for those individuals who have a "permanent affective disability". The assessment, funding and planning process of NDIS, page 17 of draft overview, would apply to this category of disability within tier 3. They, like others in tier 3, may also need support outside NDIS, such as clinical needs, which NDIS could coordinate with the area community mental health service. There are also NGO specialist care providers for these disabilities, just as there are for other categories of disability. There is a model in Queensland that addresses this group, which I think may have collapsed due to lack of funding, which NDIS could draw upon when developing its own assessment and funding of same. I have an outline of this model, if the commission is interested.

MS SCOTT: Yes, please, we are.

MS RAPHAEL: It is incumbent upon this commission to thoroughly assess and determine the numbers and nature of the care needs of those with a significant affective disability within our Australian community. The National Advisory Council on Mental Health would have access to this data, the needs of this group and how NDIS could best represent and fund them.

Secondly, I would like to address the issue of service/care provider contracts when an NDIS recipient chooses one to partially or totally provide their care. I believe it is critical that there be a formal/legal contract or agreement between the provider and client to protect security of funding, safeguard the client's services, protect the client's rights and so on. This would concurrently foster accountability by the provider.

The Community Aged Care Package, CACP, agreement is a very good model of a legal agreement for NDIS-accredited care providers. It includes schedules that delineate such services as types and hours of care to be provided, clients' rights, complaints procedures, et cetera, as well as nationally standardised compulsory schedules pursuant to the Aged Care Act. Such a model of agreement could be formulated to meet the NDIS charter. It would form the mandatory backbone or scaffolding, however you like to put it, of any such agreements, which could also make for easy assessment and accreditation of NDIS care providers. The care providers could include schedules specific to their own organisations within that framework.

Standards of care, which is something that is within these aged care packages - these may be delineated in these agreements. They need to have legislative teeth if NDIA is to realise its admiral commitment to choice and empowerment of the disabled and appropriate quantity and quality of dignified care for them. As such, these agreements would need to be pursuant to and underpinned by an envisaged act of parliament such as a disability care act, just as there is an aged care act. It may be that legislation for NDIA which is proposed in the recommendations will encompass the equivalent of such an act. I have a copy of a CAPS agreement I have had experience with in the past, if the commission is interested.

MS SCOTT: Thank you. We would be.

MS RAPHAEL: Thirdly, I would like to comment on block funding of people in community residential disability care. This model of funding does not permit or ensure an equitable spread of resources and care across the clientele, nor does it foster the provision of and meeting of individualised needs and client control over their care. Conversely, it tends to institutionalise care. Whilst NDIS proposes block funding would become defunct under its model, it still needs to address this problem for those who are or will be in residential care.

Lastly, I would like to see the commission recommend and promote legislation for the adoption of the UN Rights of Disabled Persons, or at the very least include this declaration in the proposed Australian government legislation for NDIA. This would, of course, be central to the charter of NDIS and enshrined in the NDIS client packages I referred to earlier. The time is right for this, as this opportunity may not present itself so easily in the future. Thank you.

MS SCOTT: Thank you very much, Lyn. We would welcome the material you've suggested.

MS RAPHAEL: Yes, I'm just not sure of the legal ramifications on that agreement I have, the CAPS agreement.

MS SCOTT: We've also got an inquiry going into the aged care system which you're probably aware of.

MS RAPHAEL: Yes.

MS SCOTT: So we don't actually need your agreement - or the agreement that you're aware of. I can actually get that from the other team, if that suits you better.

MS RAPHAEL: Because it just has some of the schedules of the organisation and things.

MS SCOTT: I'll get an example from the other team, so don't worry about passing that one over. But you did mention the Queensland example of a scheme for people with mental illness that you said had now effectively gone defunct because they had run out of money.

MS RAPHAEL: Yes.

MS SCOTT: Could you, either now or - - -

MS RAPHAEL: Yes, I could expand a little bit on that.

MS SCOTT: That would be good.

MS RAPHAEL: I'm not sure, I think it's fallen through because of funding issues, but it was actually called the HASP process. It's basically for someone who's got quite a severe disability who usually presents - usually coming through the hospitals, because it's just like a revolving door basically. What I'm concerned about is that HASP would not want to replace NDIS. I think NDIS should take over the role of like DSQ in Queensland, Disability Services Queensland.

So they have a jigsaw-type puzzle here, where there's a facilitator from DSQ regional office who makes a link to housing - HASP is Housing and Support Program - through to integrate that with mental health for their clinical needs; for their non-clinical needs, to go to an NGO; and then for their housing needs, to go to the housing department. So I would envisage that NDIS would take over that DSQ, because that's where the funding is not.

MS SCOTT: Yes, all right.

MS RAPHAEL: So that their packages are individualised, basically.

MS SCOTT: Okay, and that's material you've got on that.

MS RAPHAEL: Yes.

MS SCOTT: All right, I'd be grateful to get that, thank you.

MS RAPHAEL: Yes.

MS SCOTT: John, some questions for Lyn?

MR WALSH: Yes. Thanks very much, Lyn. That was a very clear presentation. You noted in the little note that you sent us - but I must have missed it if you spoke about it - the provision of emergency funding response.

MS RAPHAEL: Yes, because of the time limitation I felt I had to leave that out and go to the things that I thought had greater priority in the time that I had. But what I was referring to there was, you've actually got a small little clause somewhere in there about crisis, in a crisis. What I was referring to was an immediate emergency response funding to someone who is in a crisis, such as a parent who's the sole carer - or there's a bit of care coming from the community, but not much.

They're the sole carer, they fall ill, say a heart attack, go to hospital; they've got an adult child or a young child and they're left completely stranded like that. So support services might be coming in every morning to do a shower and then in the afternoon to do something else. What happens in the meantime? That person is in serious crisis, they need the emergency funding immediately, so someone has got to get in there and look after them, basically. Or a situation I have experienced myself twice, where I haven't had sufficient family support to pick up the pieces when I've had downturns in condition and ended up in hospital unnecessarily, protracted periods in hospitalisation, no disability care, can't get the adult lifestyle support pack, can't get the aged care package because I'm too young, and it goes on and on.

In fact, that is why I ended up in a nursing home. I didn't need to. If the funding and emergency response assessment team were available to prevent that, I may, in fact, not have got as bad as I did, shall we put it that way. I think it's actually preventive in preventing. There's no point saying, "We'll give you extra funding in this project." Hello: one week, two weeks, gone, too late, the person's passed the crisis point to the point where they've gone into something inappropriate for them or in protracted hospital - and everyone wants you out of hospital. So nursing home, residential for this child, whatever, that'll do. "Haven't got any beds there. We've got beds at the cerebral palsy. They can go there," or, "They've got autism. They can go there," wherever.

It's like mental health as well. You'd be on the streets basically; that's it:
"No beds left in the hospital, sorry. Can't have any more acute beds, sorry."
Out, no accommodation, on the street, very vulnerable. That could happen to anyone able actually, anyone able-bodied. But it's just not good enough to offer that three, four weeks down the track. So I'm thinking in terms of an emergency response team,

which I know is a pretty big thing. That's for everybody, but particularly those in the vulnerable situation of being at home by themselves, which was my situation. I think there's probably lots of examples, but where an older parent or - this happens all the time. That's why people are inappropriately placed or go through tremendous suffering or starvation.

This is what happens. Sorry, I'm getting off the track. But that's why I was also referring to the importance of having the legislative teeth within the client agreement with the care provider. And people speak about retribution. I've experienced all that; confidentiality being breached. Retribution can be not turning up to give you your service so you are left without food; you're actually left starving.

MS SCOTT: Is this because you complained?

MS RAPHAEL: No - well, yes, or else there's no service. Often there's, "Sorry, we can't send anyone to bathe you today." "Sorry, we can't get anyone to come and cook you dinner today." "Sorry, stuck in the bed? Gee, wow, starve." Now, this is happening all the time and I'm assuming that this is what this is all about, is trying to stop at least the worst things and giving control to people. So if you complained about that, yes, there are subtle forms often of retribution.

That's why I was really big on the legislative teeth, so that there's not only this channel to go through a complaints procedure - complaints procedures now, everywhere, have no teeth, it's meaningless. You can have complaints going on for a year, two years, three years, and nothing happens, nothing gets changed. So the standards of care are meaningless, because there's no-one saying, "Sorry, it's the law. You have to provide this standard of care. You can't leave that person starving without food."

MS SCOTT: Okay.

MS RAPHAEL: That's what the emergency response was about.

MR WALSH: Thanks, Lyn.

MS SCOTT: Lyn, you've given us this challenge that you think we should have an additional criteria on the eligibility group which is effectively for, in the broad, anyone with mental illness of sufficient severity they have long-term support needs.

MS RAPHAEL: Yes.

MS SCOTT: One of the reasons why we grappled with it - I know you say that the figures are available, but it's actually hard to get figures for people who actually need the type of support that we're talking about.

MS RAPHAEL: Yes.

MS SCOTT: There are lots of figures about people who have got affective disorders but, as you know, with therapy and with time, they can recover and be well again.

MS RAPHAEL: Well, no, I'm talking about the group who don't recover. That's what I'm talking about: the ignorance. In fact, there is a huge percentage; I was trying to emphasise that. They end up on the street. This is really serious stuff. There's no roof over their heads; no food; no nothing: these people who are that severely affected they actually need self-care. They can't give themselves self-care. They need someone to say, "We have arrived here. Now you need to have a shower. Now we'll get your clothes out." It's just the same as someone who has got a physical disability or an intellectual disability: they need their food prepared; they need someone to do their shopping. It's no different. That's what really concerned me. I know you want to include them but how do you? That's why I've made those suggestions.

MS SCOTT: Okay.

MS RAPHAEL: They should be included, and I'm assuming that the advisory council, who are very active at the moment and not getting very far, should have some idea, through the hospitals, at least, and the mental health system, who is going out into the community, who is coming through the revolving doors. There's got to be some record. You probably won't like it because it will add to the - it won't be $6 billion; it might be a bit more than that. But they can't be left off. It is just blatant discrimination. I'm sorry. I know. I feel strongly about it, and someone needs to speak up for them because they are often a voice that is never heard.

MS SCOTT: That's true. John, any further questions for Lyn?

MR WALSH: No. Thanks very much, Lyn.

MS RAPHAEL: Thank you.

MS SCOTT: Thank you for coming along today.

MS RAPHAEL: Thank you.

MS SCOTT: It's my pleasure now to welcome to the table Melissa Locke. Melissa, I understand you are representing the Australian Physiotherapy Association. Is that correct?

MS LOCKE (APA): Correct, yes.

MS SCOTT: Melissa, we've allocated 25 minutes for you to make a presentation but please allow some time for questions as well.

MS LOCKE (APA): Indeed. Thank you for the opportunity. I should clarify that I'm not the CEO of the organisation; I'm the national president. That means I'm a practising therapist as well as a clinical physiotherapist. The Australian Physiotherapy Association is the peak body representing the interests of Australian physiotherapists and their patients. It's a national organisation with a branch in each state and territory, and specialty subgroups in the areas of paediatrics, neurology, gerontology, cardiorespiratory and the like.

The APA corporate structure, for your benefit, is one of a company limited by guarantee. The organisation has approximately 12,000 members, with national registration. We now can say there's 21,500 registered physiotherapists in Australia. We have 70 staff, and we have approximately 300 to 400 engaged members who are volunteers who support the rest of the profession on committees and working parties governed by the board of directors, of which I'm the national president elected by representatives of those stakeholder groups within the association, so that you know where we come from.

MS SCOTT: Thank you.

MS LOCKE (APA): The APA vision is that all Australians will have access to quality physiotherapy, when and where required, to optimise health and wellbeing. We have a platform and vision for physiotherapy 2020 and our current submissions are available on our public web site. The APA strongly agrees with the Productivity Commission that the Australian disability support system is in dire need of change. As mentioned in the APA's initial submission in August last year, physiotherapists who work in the disability sector, or who have patients or clients with a disability, have long been concerned about the uncoordinated way disability services are funded and provided. The APA strongly supports the establishment of National Disability Insurance Scheme and a parallel no-fault scheme to address catastrophic injuries from accidents.

More specific comments relating to the commission's report will be submitted in a formal response, which we are currently completing. For the public hearing, the APA would briefly like to address three key points identified as significant aspects of the scheme most relevant to physiotherapy. The first one is "assessment tools". The APA is pleased that the Productivity Commission has recommended the use of the international classification of functioning, disability and health as the framework for which assessment tools will be based on and/or developed. We believe that assessment tools should measure an individual's capacity rather than their function. For example, a person's ability to perform a specific activity such as walking or talking may not be an accurate reflection of whether the person has the capacity to engage in the social environment or in the environment.

A good example is a girl I'm caring for at the moment who is dyspraxic. She can speak but she can't form her speech in patterns that allow her to communicate without assistance. Another example is a boy I treated last week, whose condition is one where the nerve fibres that supply his muscles allow him to jump and run but he can't walk. Therefore it is seen as interesting that this boy can suddenly jump or run when he's excited, but needs assistance and disabled parking, and is seen as a pariah, as someone who is abusing the system.

"Service navigation" is our second point. Physios have a vital role to play in the initiation, facilitation and provision of care for people with a disability. We're well placed to assist people with disability and their carers to set goals, plan long-term management, perform specific physio interventions to optimise health and wellbeing. I've been a paediatric physio, a specialist clinical physio, now for 21 years. One of my boys currently, who initially was brought to me for management of a musculoskeletal condition, had cerebral palsy and he had a scoliosis developing. From that time, we have supported and navigated him through to high school, mobility devices, management of his scoliosis, the need for single-event multilevel surgery in his lower limbs to allow him to continue to walk in the home, a manual chair to allow him access to the science lab at school, a power chair to allow him to get to the library or the oval.

We've been involved in coordinating access to VET training so he can have post-school options. We are looking at the way he can use a car in terms of the adaptations. This isn't physiotherapy alone, but because I have a relationship with him I have been the coordinator of that: to have a boy who we really thought had little option of completing school to being someone who is engaged and looking forward to working in the community.

On this point, a physiotherapist or another health practitioner acting as an intermediary for a person with a disability can play a significant role in designing the initial personal plan during the self-assessment process. This should not be reliant on other systems in health where the GP is the gatekeeper. I'm not saying that at some time the general practitioner is not appropriate but, very often, other health practitioners will be more involved and will understand the needs of that family and that individual. We have the knowledge - physiotherapists - and the training to anticipate when and what interventions, aids and equipment are needed through the lifespan of a person with a disability.

I have real concerns when a legal counsel asks me to predict what the cost of a child will be up until 18 or 21 with a disability, and asks my expert advice. It is a crystal ball activity and if there is a constant funding process in place that allows that, you will see that people won't fall through the cracks or be disadvantaged.

Intermediaries should be appropriately remunerated for the time and expertise, for example through a rebate like the Chronic Disease Management Plan, or else it won't be done well. It will be tick and flick or a less qualified person doing that and getting the money that is available. A registered health practitioner should be the intermediary but they should also be allowed, we believe, to provide the relevant services. I'll use physiotherapy since I'm here as the representative of the APA. If we act as the intermediary we should be allowed to provide the service if we are the best-placed person to do that, especially in the rural and remote regions where there is a lack of registered health practitioners with skill and expertise.

This, as well as access, has benefits in preserving the continuity of care for the client. We do realise there's a potential risk of this arrangement and we do know that the commission has seen that, so a strong auditing process should identify any anomalies or discrepancies. A safeguard as well is that a registered health practitioner risks facing disciplinary action from their relevant board, which is a strong deterrent.

Our third point is the use of lists to determine eligibility to interventions, supports and aids. As a component of assessments for eligibility of services and supports - for example, aids and equipment - the APA acknowledges that for practical reasons a list would be the most appropriate and efficient and quickly used to determine eligibility. I'm sure that the commission is aware there are gaps in lists where cost-effective interventions or supports may be overlooked or excluded. For example, some interventions or equipment may cost more but produce far better outcomes for certain impairments, such as being able to bring a person with a disability to a higher level of functioning that would allow a high level of independence to self-manage their care or return to work - whatever.

The APA reiterates there's a need for an approval process that looks at requests for interventions and equipments outside a pre-approved list. We can't stymie innovation. I'm currently treating a number of little children with arthrogryposis, a musculoskeletal disorder. They have normal mechanisms of development movement but their musculoskeletal deformity prevents them very often from walking independently. They're often quite short in their stature. One little girl at the moment - there were no walking-sticks of a size for her to use. A walking frame was inappropriate because that's not what she needed. She was going to walk independently. So we developed toilet plungers as a mechanism for her to walk independently. It was an amazing thing to see. We raced down to Mitre 10, bought a couple, and she walked in that session.

So the innovation needs to stay but we realise that there needs to be a panel of experts relevant to conditions and intervention of equipment, to see that it's appropriate, so there needs to be a regular review of those lists. Perhaps the commission could also explore a parallel process for equipment manufacturers to apply to have equipment included on that list. There has been the most amazing chair - a power chair - that has had many years of development in America. It came to Australia recently. It was approved on German safety standards but the process to go through the Australian safety standards is very rigorous. This is a mobile power chair with a sharp turning circle. It's lightweight. It can recline when the child is fatigued or has a seizure. The company has gone bust because they just couldn't get the project out there because of the red tape to have approval of this. I think that's enough for me to say and I'd welcome any questions.

MS SCOTT: John, would you like to start off?

MR WALSH: Thanks, Melissa. You've covered a lot of ground there. I've got a number of questions. Let me start first of all with the idea of the model of care. You've said in a number of places it costs a bit more to get good outcome. Physiotherapists are expensive and I wonder whether you've given any thought to the place at which physios would hand over, or could hand over, to less qualified but less expensive support workers who could nevertheless work under a less intense physiotherapy instruction.

MS LOCKE (APA): I think it's imperative that it happens, John, across all healths. We have an ageing health workforce, we have an ageing population, we have a significant group of people with disability. Medicine, improved outcomes of care have resulted as a consequence of that. The APA is committed to the establishment of physiotherapy assistants in the first instance. We have a great attrition of physios to medicine, law, because they realise that perhaps what they studied for isn't appropriately what they do in their work in certain instances. There is a need to give that work that is less problem-solving work to another group. It may be exercise physiologists - not that I'm saying they're less qualified than physiotherapy. It's just a different set of skills.

In the rural areas there are generic therapists, there are nurse practitioners. I think physiotherapy in the past has held its knowledge too closely and we need to change that and we're certainly doing that already within the association and the profession. I have a lot of communication with the heads of the schools across the universities in Australia and New Zealand who realise the need to do this. There's a great appetite for that.

MR WALSH: Thank you. Any information you've got on the time frame of that would be useful. As you know, most of the other professions that you've mentioned are already down this path.

MS LOCKE (APA): Yes.

MR WALSH: We're talking now about doctors assistant. Do you have information on the APA's plans to roll that out?

MS LOCKE (APA): It's out there already, John. There's a certificate IV in physiotherapy assistants. At a state level I can tell you, here in Queensland, the Princess Alexandra Hospital I think produced 100 physiotherapy assistants last year. I will give the commission those details on the different places across Australia that are doing this training.

MR WALSH: That's good. Thank you. You talked a little bit about the potential dual role of being an assessor and a provider. You noted that we've regarded that as a conflict of interest, which we do. If you could provide some examples on where that works well and is contained in a cost-effective way, that would be useful.

MS LOCKE (APA): I certainly will furnish more of those with our final report but, as an instance, I think I gave an example in my preliminary comments about the rural and remote area where I also see that you'll need more and more generic therapy or physio assistants or trained carers to do activities. That would definitely be a place where it would work. In my experience in paediatrics, for continuity of care: the parents believe that you understand the child and the goals, hopes, dreams and aspirations.

I was thinking about this on my way in this morning. Perhaps in that model, that would be a system where one within a group might provide the care, or assess, send out to other areas - whether it be less expensive providers of service, or other physiotherapists within the group if physiotherapy was the thing that was needed at that point in time, because there will be acute episodes in the journey of someone with a disability where they need physiotherapy care, but that will be costed under a different system, I would imagine. I imagine that is an opportunity, a place where it could work. However, you would need very rigorous auditing and you would need to know that those people are bound by their registration board act and code of conduct.

MR WALSH: Thanks, Melissa.

MS SCOTT: Do you see that arrangement going to where - the person who's the intermediary also providing the care. Do you think that would only be for people in regional and remote areas?

MS LOCKE (APA): I can see that's a more appropriate and more appealing option for the commission. I would hate to see someone have a lesser outcome as an individual because it was seen that it could be high-risk, but you would have to weigh up the benefits of both and that's something that perhaps we as an association have to explore a little bit more - options to give you in our report that could work better so we could have a meeting of the minds.

MS SCOTT: Okay, because we're conscious of the threat of overservicing where a person with training advises you that you need 80 sessions and so on, so I guess I would have an interest in whether you only see it for regional and remote areas. The other thing I'd be interested in is any information on distribution of your members in rural and remote areas of Queensland. I mean, sometimes people refer us to the paucity of services and certainly we've heard evidence to that effect in New South Wales at the regional hearings. I'd be interested in whatever you can provide in terms of the geographical distribution of your members who are active. That would be good. Do you want to say something?

MS LOCKE (APA): No, that's all right. I will talk about those two things.

MS SCOTT: In relation to peer assessment of equipment, your example of the toilet plunger is a good one. Yes, there are sure to be lists if the scheme is adopted by governments. On the other hand, you always want some flexibility around and why would you go for a high-cost alternative when there's some innovative approach required? Your organisation might wish to chance their arm at what a recommendation would look like for that because, as you'll see in the text, we've talked about effectively clinically proven technologies.

A scheme that we're interested in in New Zealand uses a phrase of "fast follower"; not at the cutting edge, not being necessarily experimental, but once it's clinically proven then adopting a technology. Look, we'd be interested in what you can suggest in terms of the wording of a recommendation there.

MS LOCKE (APA): Sure. We're happy to do that.

MR WALSH: We had evidence given the other day, Melissa, by a branch of TAD, which I'm sure you work with. I'm sure those guys are able to implement some of the more innovative ideas you have that might not be available off the shelf.

MS LOCKE (APA): That's certainly a group we use quite a bit and that's a beautiful system in existence because it allows the therapist or the family indeed to approach TAD and have an outcome quickly. It might look messy, might look a bit rough, but it's infinitely affordable. It's also wonderful for those people who are involved in offering a service; who are retirees, or just people who have a desire to help and skills to give it.

MS SCOTT: And one last question about something you haven't mentioned at all but I think I can make a connection back to some of your presentation, and that is at tier 2 we're talking about a referral service for people who may not receive individualised packages but are still looking for assistance in terms of where supports are available, what assistance can be required. In the report we refer to it as - you know, for some people it could be a web site and for other people, where they wish, it could actually be someone from the organisation helping them to make the connection and not only just telling them about the service but potentially making an appointment and so on.

Now, we've talked about the "confusology", the incredible maze of services that are out there now. In your presentation you pinpointed the issue that often physiotherapists are able to help people navigate their way around because it is very complex. Maybe you'd like to take away and advise us how long you think it would take to bring together, for a region, all the services that are out there. Maybe your members already have informal handbooks or maybe you're aware of all sorts of - I know that in various cases there can be material available on different web sites, but what we're talking about is someone bringing this all together.

Then I guess the issue is how do you quality-control the information on that web site, given that you could have swim with dolphins type therapies seeking to have themselves listed. So I'd be very interested in how you would see that developed, what resources in your experience could be usefully used, how long you think it might take to get material well done, and then how do you ensure quality control? But I think that's probably enough homework. John, what do you think?

MR WALSH: That sounds like - what kind of time have we given? You've got I think about two weeks.

MS LOCKE (APA): Two weeks' turnaround? It's just that we're working very much with Better Start for Children with Disability and there are so many things there. Swimming may be very appropriate for children so that they can participate with their peers and their siblings, especially in Queensland, but it's not approved but hydrotherapy is. Hippotherapy is seen as a therapy - horse riding for people with a disability - but Riding for the Disabled isn't. There are things here that are going to be huge for the commission, and for that group as well, and I'm not sure how it's going to all dovetail together ultimately.

I will definitely get the demographics of our members to you. I've been thinking just as you were speaking, Patricia, about the way you would audit if someone was the intermediary and the provider. A model of care that works very nicely in the private sector is that - and QBE is a proponent of this and it's happening, I know, in Western Australia and in New South Wales. Veterans Affairs do it as well, where there is a specialist physiotherapist who audits each case to see a yellow flag or a red flag.

We as physiotherapists now have a college, we've had it for 40 years, so there are specialist physios in all areas. They are the people called upon in these roles. They look at a physio's occasions of service and their notes and the reports back. Certainly with the electronic health identifiers and the patient records that are coming into effect next year, that potentially could make it easier, where they see things and they speak with the therapist, so that could be an option for that. I will work on tier 2 as well. I didn't quite know that I'd get all this homework but we're very happy to do that.

MS SCOTT: Thank you very much. Examples can be very telling in a report, as you will have seen from having a look at the larger report.

MS LOCKE (APA): Yes.

MS SCOTT: We do like to use examples because that assists people to understand. So thank you very much for the use of the toilet plunger example today. If there are other examples where you're seeking flexibility or there are examples where things work well, please include them. They can be very telling.

MS LOCKE (APA): Yes, we will.

MS SCOTT: Thank you very much.

MS LOCKE (APA): Thank you.

MS SCOTT: We're staying on time, John, I'm pleased to say, and now welcome to the table Angela Tillmanns from the Cerebral Palsy League. Angela, we've allowed 25 minutes for your presentation, and also if you could keep in mind that we will be asking questions. Thank you for coming along today.

MS TILLMANNS (CPL): Thank you very much. First of all, I just wanted to say congratulations to the Productivity Commission on their great work. The recognition that the disability sector needs transformational change is welcomed by the Cerebral Palsy League, as is your acknowledgment that the disability support system as it stands is broken and fragmented, resulting in an inefficient, ineffective service delivery. It's great to see that people with disability in Australia are finally being heard and that their lack of choice and assurance of funding levels is simply unacceptable in the 21st century.

While the Cerebral Palsy League will respond in detail to the questions raised in the draft report, I want to use my time today to highlight three key points that have consistently emerged through our consultation with the 5000 people that we support who have primarily physical disabilities: the first is the philosophy underpinning the design of the system; the second relates to how children are supported under the proposed scheme; and the third relates to assessment.

On the first issue, the Cerebral Palsy League is keen to see that the design of the scheme empowers people with disability to maximise their independence and contribution to society, not just provide care and, thereby, continue a dependency on government or community handouts. We need to fundamentally change the way we approach disability in this country, not just change the funding regime, and this report provides us with an opportunity to do that. This is a once-in-a-lifetime chance to bring people with a disability into our society as full participants, to move to supporting participants in the scheme to actively take opportunities, not just passively seeing what those opportunities may be.

To achieve this, the Cerebral Palsy League would encourage that all support under the scheme needs to work under the principle of support to what purpose, what outcome. The scheme needs to focus on encouraging and resourcing the support alternative that brings about the greatest opportunity for the next level of independence, whatever that might be. It can range from switching lights on in your own room and changing TV channels right through to being in full-time employment.

The scheme needs to transform the premise of disability support from providing care and safety to enabling independence and contribution. This will move disability support into a consistent social policy space with education and labour market support, where the aim is to enable every Australian to maximise their opportunities and to contribute to the social and economic fabric of their communities and the nation. This approach will see outcomes in the investment of support being easier to measure, linked to people's life goals and to how we assist them to realise the greatest opportunity from every support provided. This will improve the life of the person with the disability, with flow-on effects to their informal carers and the community.

For example, why provide a support worker to hold someone's hand and do everything for them in visits to the local community when we can assist those same people to participate in community life independently and in their own right? This may be as simple as providing public transport education, a piece of equipment, money management skills, connections with the local community, business and groups, and then only providing limited personal care when and as required.

To achieve this will require a new focus for planning, one that understands and focuses on an individual's life goals and understands how they can work to the greatest effect with their provider of choice and the networks that surround them. We've recently introduced such a tool for all Cerebral Palsy League services called the Personal Outcomes Measures system, which we've adapted from a system that's used widely in the United States, and we will be providing much more detail in our written submission around that system.

One of the things that really brought home to me the value of this system was that we've provided support to some of our clients for many years - 50 years. One of those - and I'll just use a made-up name. John had been with us for 50 years. We provided accommodation. We provided community support. We'd focused very much on getting him quality personal care support and access to the community, but not within a framework of what he was trying to achieve in his life, and it wasn't until we used this new life planning tool and sat down and spoke to John about what he was really trying to achieve, what he was interested in, how he could make that connection with the community, that we found out that he loved going to the movies and he loved being the first to see that movie so he could report on it to others in the community.

We'd taken him to the odd movie here and there. That was really expensive; we had a personal care worker there the whole time; it was in taxis. But we found out that there's a bus stop right outside the front of his house. Now, he is more than capable of catching that bus, so we did a lot of work around public education with regular bus drivers on that route. He now goes and sees every movie that starts at his local cinema - because, thankfully, it is fully accessible - and he now works on our Internet radio program giving movie reviews. So his input into the community has increased dramatically, just because the service provider thought differently about the way they interacted with that person and planned their support services differently. So as a result of that, we think there needs to be a much stronger emphasis on life planning in tiers 2 and 3 in the current model.

Moving on to our second point, which is about support for under-18s, we believe that disability support should be available to all children with a disability regardless of the severity of the impact. When we look at the report it looks like only children with severe limitations would be included in the NDIS, and we're arguing that you need to think about children totally differently and have a separate strategy for children, because it links in with the early intervention that comes through so strongly in the report, as well as that investment strategy. We believe that the investment will ensure that these children will grow up into adults that will be able to be in the best position to maximise their independence and, in a very real sense, create the highest possible effectiveness of that three-tiered system that is proposed.

We've already heard a little bit about that Better Start Program, so what we'd be saying is incorporate that program that is currently being rolled out by FaHCSIA and extend it to age 18 using the already agreed eligibility criteria and the interventions that could be adapted and quite easily used. We'd then be saying that between ages 16 to 17 is when you would really kick in that life planning component and you would signal the commencement of a real transition to adulthood, and about how do you use that investment that we've placed into that child for those first 16 to 18 years and mobilise that into employment, higher education, whatever that person is going on to do.

This will ensure that a young person with a diagnosis of cerebral palsy would gain access to the therapy, equipment and support that would build their physical and emotional independence and reduce their reliance on funding in adulthood. This is also a way to bring about generational change in our society in respect to the expectations and value that we, as a community, place on a person with a disability and what they're capable of achieving.

At the Cerebral Palsy League we know that by coupling higher expectations of independence with adequate early investment in therapy and equipment, people with disability go on to achieve amazing things, requiring minimal ongoing support from government. So at a time when, as a nation, we face the prospect of a reducing labour force over the next 50 years, we can't afford not to have these kids invested in and being part of that workforce into the future. This is simply not the right thing to do; it's the only sensible thing to do from a social and economic perspective. We believe investment in all children with a disability will also address a lot of the ineffectiveness that's currently in the system, about equipment getting there too late that's no longer used, therapy getting there too late that's minimising the impact that it could have. So by including them we would actually improve the existing system.

On my last point, assessment, we believe that assessment needs to be a pathway for achieving, not a process for gathering evidence to close doors - and, my God, how many doors are there? There are hundreds of them. CPL clients, both adult and children, want one assessment point to be used across all government agencies at all levels of government. This would involve sharing information electronically across Centrelink, education, health, transport, and the proposed NDIA. We believe this is achievable, with government developing and owning the various assessment processes, providing accreditation to assessment bodies out there in the community that are disability experts, and then moderating those assessments for consistency.

The assessment and life planning process builds understanding in relationships. Therefore, it does make sense for it to be done by accredited disability experts, and we heard a little bit about that in the previous presentation. We strongly support that once that plan is developed it does need to get approved by a government body. If we could decrease the number of assessments that people with disability undergo, we would free up a substantial number of people in the disability and associated sectors to actually deliver services. There are huge savings in there.

One family that we've got at the moment, who has only recently joined our organisation, has had to get, obviously, medical reports done so that they could apply for the carer's benefit through Centrelink. They then had to get a slightly different medical report done so that they could get the disability permit sticker for their transport. These parents are starting to struggle with the state system and trying to find out what supports that they can get from there, and need yet another system of assessment that they've needed to go through, only to be told, once they've got through this entire assessment, "Oh, we really don't have any funding that can help you."

This has resulted in both parents giving up work. We've now got two people that were highly educated in the workforce that are now at home caring for a child and battling the system. So this simplified assessment system really needs to be looked at through this system.

We believe that adults could access the assessment component, both under tier 2 and tier 3 of the scheme. As we've said, with tier 3, that is where the sign-off would happen, at government, and also getting that assessment and planning process happening at tier 2, so those referrals are placed, once again, in that overall life context.

We've recently introduced these personal outcome measures. We believe that it provides a framework to assess those overall life outcomes that are important to a person and the supports that would be necessary to achieve those outcomes, and using this information or service in a much more informed position to develop a plan for goal attainment for a purpose that the assessment can be linked to achieving those outcomes. It also clarifies expectations, and all of that can be measured, so that we can give feedback to taxpayers around what's been the return on their investment.

In conclusion, I'd once again like to thank the Productivity Commission for such a comprehensive report and request that you give further consideration to a specific strategy for children, a simplified assessment system, and incorporate a stronger emphasis on life planning, to maximise independence.

MS SCOTT: Thank you very much. John, do you want to lead off? I have got quite a few questions for Angela.

MR WALSH: Thanks for that, Angela. That was a very clear presentation, and I think nothing that you've said is inconsistent with where we want to go.

MS TILLMANNS (CPL):   I absolutely agree.

MR WALSH: It's really just in how we present these things, and some of the examples you gave would be very useful; the one about John and the cinema, and the one about the two parents giving up work, in particular, are very strong examples. With children, we've attempted to achieve, I think, what you've recommended through the - you will remember in tier 3 there are three specific subgroups?

MS TILLMANNS (CPL):   Yes. There's the early intervention one, and I didn't know if that was children or not.

MR WALSH: That is largely children and the idea is to try and get to children at the most appropriate times and to support their development, as you say, in a life-planning type way. So that was the objective of that one. Patricia, I don't have any specific questions. I pretty much agree with most of what Angela said.

MS SCOTT: Thanks, John. There are certainly some themes in your address about the flavour of independence - you know, the examples that you gave - people aspiring to be more independent in their lives in terms of the degree of control, whether that's community participation or turning off the lights and so on. In writing a report that covers people with so many different circumstances, it's easy for things to be misinterpreted. It's almost like harsh treatment.

For example, a focus on independence, which I support, could be construed or misconstrued as sort of a tough love arrangement or just harsh treatment, but I thought your words were very clear. How would you think we should pitch that issue of acknowledging that for some people independence may in fact be seen as laughable, by some groups, including some parents, and yet others may well embrace the concept and think that's great, where you've got to give credibility to a report that covers people in such diverse circumstances?

MS TILLMANNS (CPL): I think we've got to think about independence as a continuum. Independence isn't just paid employment. Independence can be a whole range of things. We see that with severities of cerebral palsy. There are some people that have such high levels of cerebral palsy and, coupled with other disabilities, really all they can do is just blink and have eye-gaze technology. As I said, that enables them to turn on and off their lights, choose their TV programs, start to communicate a little bit using the Internet. Even that brings greater dignity to a person and a greater quality of life.

In all our discussions we've had with clients, what they've talked about is they don't want another great system that improves the way they get a handout. They actually believe they are worth investing in and they want that investment, because we know they can do so much and, with a little bit of help, they can do so much more. That's the strong theme that keeps coming through. But when you back that up with a society that goes, "Oh, this poor person with the disability, let's treat them as a victim and pity them," as well as then a system that just says, "We will give you the scarce resources that you need to survive," we're just not getting the payback that these people are capable of giving.

MS SCOTT: That sense of achievement and payback, or the investment in the individual and the return to the community, the return to the individual, as an economist it sounds quite appealing, but I'm just conscious of the wider audience. Do you think that's something that people would generally accept or do you think that could be offensive to some groups?

MS TILLMANNS (CPL): No. I think they would broadly accept, but what we need to make sure is that there's a welcoming community for these people to go into; it's both sides, which I think is what your tier 1 is trying to create, that welcoming community.

MS SCOTT: Yes, that's right.

MS TILLMANNS (CPL): That's why I think the trials around where we do this have to fundamentally think differently about the way that we deliver services to people with disability, working with parents around different expectations that they have of their child with a disability, differences in schools. There's a whole range of things that we have to do. I think if we structure the trial properly, we will actually be able to use this as a lever to dramatically change the way things are done rather than just improving what's already there.

MS SCOTT: Angela, I certainly would welcome examples of achievements in terms of independence. That would start with the technology that helps you change the TV, through to employment.

MS TILLMANNS (CPL): Yes.

MS SCOTT: Seriously, all the way through.

MS TILLMANNS (CPL): We can do that continuum.

MS SCOTT: That would very, very useful. You would have seen in the report that we often use boxed examples that allow us to illustrate things, and I'd welcome as many illustrations as you can give. Especially, if you're comfortable in referring to actual cases, obviously with name changes to protect the people's privacy, that would be great.

MS TILLMANNS (CPL): Yes.

MS SCOTT: Any further questions for Angela, John?

MR WALSH: There's just one, Angela. The change you're envisaging - and I think it's consistent with the commission's vision - is a fundamental change to the whole system. Would you mind talking a little bit about whether you think that's most feasible with a national approach or to ask each of the states to do that individually?

MS TILLMANNS (CPL): Look, John, I've probably got a bit of a bias. After being a Commonwealth public servant for 30 years I'm pretty in tune with federal systems. I actually think the federal systems are the way to go. The reason for that is because of the duplication of effort I see. Even purely in doing disability policy in this country, we've got every state government doing it and we have a federal government doing it as well; you know, assessment processes that vary between federal and state levels.

If we could just have one approach, I think it would simplify systems enormously, but I also think it enables us to drive change much more effectively. It's certainly something we've looked at from an organisational perspective as well. We've been very state based, because that's how the funding has flowed, but are now looking to join up with all of our other organisations to have a national approach and we're seeing advantages in doing that, as an organisation - in making savings as well. It's about having those local connections fitting into a national strategy.

MR WALSH: Any examples you can think of, of those advantages, would be very welcome.

MS TILLMANNS (CPL): Okay.

MS SCOTT: Angela, I suspect that you're envisaging the tier 2 more than we might have allowed for in the report. We talk about information referral, web services and so on, but in your presentation you talked about, I think, life planning and so on, which I - - -

MS TILLMANNS (CPL): We're not seeing that life planning would take an enormous amount of time, but it would be something where you'd sit down and have a structured conversation so those referrals had some context. Yes, we are seeing a little bit of a struggle.

MR WALSH: As far as the tier 2, that life planning would involve use of mainstream services for the most part?

MS TILLMANNS (CPL): Yes, that's correct.

MR WALSH: Do you see that there's any feasibility for us to transition some of what we're calling tier 3 into tier 2 if life planning was a significant component of tier 2?

MS TILLMANNS (CPL): Yes. I'm not saying it would be large numbers, but yes, I think that should be an expectation and a goal, with the understanding that if you go from tier 3 into tier 2 - if your circumstances change - you can always come back to tier 3, yes.

MS SCOTT: Thank you. John, any further questions?

MR WALSH: No. That's all from me. Thanks, Angela.

MS TILLMANNS (CPL): Thank you.

MS SCOTT: Thank you very much. We might just take a short three or four-minute break now. So if anyone wishes to get a cup of tea or coffee. We're going to return to have Azan Mann present.

MS SCOTT: Good morning, Azan. Welcome to the inquiry. I understand you're representing yourself. Is that correct?

MR MANN: That's right, yes.

MS SCOTT: Okay, good. All right, we've allowed 15 minutes for your presentation, so please start now.

MR MANN: Mine probably isn't as cheery as everyone else's. Commissioners, in May last year I sent a written submission wherein I predicted that the real aim of the commission would be to strip from the disabled pensioner, remove the pensioner from the disability support pension and create yet another layer of government bureaucracy at incredible expense to the taxpayer. Well, now we have the draft report. Have I been proven accurate or merely uncovered as another loony-fringe disabled and disgruntled individual?

Well, the draft report recommends - surprise, surprise - (1) the creation of a new bureaucratic structure, the National Disability Insurance Agency, which by necessity would be larger than Centrelink with duplicate requirements to manage (2) a disabilities insurance scheme and a national injury insurance scheme; (3) an extra $6 billion of new funding to be garnered from the poor overstretched taxpayer and the centralisation of existing disability funding into the National Disability Insurance Agency bureaucracy; (4) three loosely defined categories for disabilities, category 1 being mild, to 3 being significant core activity limitation; (5) the dramatic reduction of those currently in receipt of the disability support pension to help offset the costs to implement this new bureaucracy; (6) the onus placed on government to dramatically tighten eligibility to the disability support pension; (7) the outright denial of access to the National Disability Insurance Scheme to those suffering from catastrophic injuries to be covered by the new National Injury Insurance Scheme - terminal illnesses to be covered with an existing palliative care; musculoskeletal conditions and back injuries to be covered within the existing health system; category 1, 2 mental health disability to be covered within the existing mental health system, and those currently in receipt of a disability support pension suffering from category 1, 2 disability, in order to protect this scheme from initial pressure and cost blowout.

As someone currently in receipt of the disability support pension I am therefore extremely concerned that I and all those like me without a voice are to be shut out from this scheme and either left on the pension - an income recognised as being well below the Henderson poverty line - to rot, or removed from the pension altogether and literally forced by government back into Newstart to work whatever hours, even by minimum - page 48, draft recommendation 4.6 - and for slave wages set under the Department of Housing, Community Services and Indigenous Affairs at as low as

$1.79 per hour - that's a quote from Nojin and Prior v Crown - with no regard to circumstance, lack of transport, remote location for those of us who live in the bush, et cetera, or the rent factor, where average rent for housing in capital cities, recognised by government - Australian Bureau of Statistics 2010 - is $370 per week in Adelaide, being the cheapest, and $470 per week in Darwin, being the most expensive, with the Australian mean rate being $420 per week.

And the disability support pension is how much a week? Unless I'm being underpaid - and I know I'm not - I receive a meagre $415.65 per week and that includes rent assistance, namely an amount less than the average cost of rental accommodation. This fact alone, ignored by the commission and both sides of government for decades, simply forces the weakest in society into homelessness or substandard, illegal or cramped accommodation where abuse and neglect are commonplace, to the further detriment of the individual, whole families and society in general.

The only beneficiaries of the commission's draft report that I perceive are a minute percentage of the population currently suffering - or who will, in the future, suffer - a category 3 disability, all of the countless numbers of bureaucrats to be employed and richly remunerated under the new National Disability Insurance Agency, and the associated public, private service providers and insurers, who seem more than keen and enthusiastic to claim a huge slice of that $6 billion of new taxpayer funding, as confirmed by the Disability Alliance in their travelling information seminar which was held in Lismore on 30 March 2011, their web site address being everyaustraliancounts.org.au.

I am also appalled that the issue of mental health, recognised by all to be in crisis, remains unaddressed by this draft report, with the only mention being page 12, dot point 2, and page 46, draft recommendation 3.4. Moreover, the commission's recommendations - along with inspired comments voiced by the Leader of the Opposition before the Chamber of Commerce in Brisbane on those in receipt of the disability support pension - traumatically placed extra anxiety and stress upon the most vulnerable in our community, as if the weakest and most easily ignored in society could once again be used as scapegoats, footballs and targets by those in power when it comes to discussing the cutting of services or enforcing Draconian policy, something that is actually deemed bullying behaviour and victimisation in every other setting but this. Personally, I doubt that any politician understands the negative health effects these verbal proclamations and proposals have on the life of someone with a disability and in receipt of a pension, as if the lessons from tragedy and horror, like the Port Arthur Martin Bryant incident have not been heeded at all.

Furthermore, the models the commission proudly bases its recommendations upon are the New Zealand, UK and USA models. Unfortunately, over 65 per cent of inmates in American prisons have been found to have a background of mental health disabilities, and the cost of the individual in the prison system to the taxpayer is, as we all know, many times the cost of a disability support pension. The UK is also experiencing a blowout in its prison population from those suffering mental health disabilities. As for New Zealand, not even the Kiwis want to live there - and I should know, I left in the 70s, and every year I see more and more follow, as if in exodus. That should tell anyone which current model benefits its own population, and it certainly isn't New Zealand's.

In New South Wales, where I reside, under the umbrella of human services there is already an excellent Department of Ageing, Disability and Home Care that provides for all of the needs within the community for the most severely disabled; a New South Wales equivalent WorkCover scheme to meet the needs of all workplace accidents, injuries and rehabilitation is available in all states and territories; medical malpractice and misdiagnosis is also something that is more than adequately covered by the legal fraternity; and insurers already cover road and home accidents that lead to a severe category 3 disability.

Nevertheless, I am not saying that the current systems would not benefit from a tweaking every now and again, and I am sure all would benefit from any such massive boost in funding, instead of being consumed or totally replaced by the proposed National Disability Insurance Agency, something that implies that all of these current systems are failing to deliver service.

I, for one, simply cannot see why any government would ever advocate another bloated bureaucracy - something the commission recommends - just to cater for a tiny percentage of the disabled population. This would be hypocritical in the extreme when both major parties in government decry duplication and waste. Disturbingly, the draft report does not even inform, in a pie graph or chart of any description, the proportion of proposed funding required for the new bureaucracy to function compared to the actual funding available for the disabled recipients; namely, is this a proposed blank cheque for bureaucracy and associated service providers if ever there was one?

Here, as a useful comparison tool: after the billions of taxpayer dollars spent so far in subsidising the numerous private Job Network providers who took over the role of the old Commonwealth service when that was deemed as an inefficient use of taxpayer dollars, the long-term unemployment rate still has not fallen at all, and why isn't anyone questioning the actual cost of that policy change? Therefore, why would anyone in government or the public be fooled to believe that those even more difficult to be placed in employment - namely, those of us currently on the disability support pension - would find their chances, care and support even more optimal, especially when being denied the extra funding from the National Disability

Insurance Scheme to improve their lot? It simply beggars belief.

No rational employer currently takes up the opportunity to employ the mentally unstable, likely to have a breakdown within the first day or week - or in hiring someone with a disability, however minor, that could be aggravated or flare up at any time - without massive government financial subsidisation and an ongoing specialist support system in place. This is not proposed in the draft report for those on the disability support pension with a category 1, 2 disability.

Personally, I am horrified at the recommendations in the draft report and the potential damage these will do to Australian society if implemented as is. One only has to look at the American, UK and New Zealand social profiles as examples - depending, of course, from which strata of society one looks. I can tell you that from the bottom they look bleak, dark and full of despair, poverty and crime, but from the top they look ever more selfish, greedy, consumerist, interested only in increased profitability and personal enrichment, with the rest of society only ever viewed through rose-coloured glasses.

However, the basic question should be: when the power and the lights fail what happens then, and in which society would you rather live, theirs or ours? Finally, as for my ability as a seer, I think I was right on the money with my original predictions, something I will leave for the commission and history to contemplate.

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

MR WALSH: Just a couple of comments for the record. Thanks, Azan. I just wanted to make the point that the costing in the report doesn't presume any savings from disability support pensions, so you may have misread that part of it. And the overwhelming evidence that we've heard around Australia is that what you call the tiny proportion of people with a severe disability is that those people are very poorly served and I think that's the group that we've been asked to try and look at in this report. So thanks for your opinions.

MS SCOTT: Okay. Azan, I don't have any questions for you, but thank you for coming along today and thank you for your submission.

MR MANN: Thank you.

MS SCOTT: Do we have Francis Vicary and Nigel Webb available? Would you like to come forward now. Ladies and gentlemen, just a point I might make before we start with the next speaker that I didn't make at the start. While this is a public hearing, it's not actually a public meeting. We need to have comments on the transcript so other people can comment on them. I will give people an opportunity at the end of the day, if they wish to, to come forward to make short comments if they aren't already on our schedule. But because we are making a recording, I would ask that for transparency reasons you don't actually make comments from the floor.
I now welcome Francis and Nigel. Could you indicate the organisation you're representing, and we've allowed 30 minutes for your presentation questions.

MS VICARY (QDN): Just for the record, we've got Janelle Tong, who is our administration officer, supporting us.

MS SCOTT: Okay, and welcome Janelle.

MS VICARY (QDN): Nigel is going to go first.

MR WEBB (QDN): Good morning. My name is Nigel Webb. I'm the current president of Queenslanders with Disability Network. My role today is to give you the introduction to our piece, and also our overview of our position. Queenslanders with Disability Network is a network of, for and with people with a disability, with over 850 members across Queensland. Over the past four weeks QDN has met with members across Queensland and held conversations on the Productivity Commission's draft report into disability care and support scheme. The overall feeling of these conversations was a positive reaction. However, there is a strong sense of apprehension as to how the National Disability Insurance Scheme would be funded, if it would remain impervious to lessening by future governments and how it would be implemented, taking into consideration QDN and its members strongly support the establishment of the NDIS and the NDIA that would meet and support the needs of people with disability throughout their lives.

Our View: QDN acknowledges and supports the Productivity Commission's view that the current system is not well funded and does not meet the needs of people with a disability in Australia. The recommendation changes will move towards developing a system of support for people with a disability that is based on entitlement, acknowledges people's citizenship and right to participate in society, and support economic participation through meaningful employment of people.

In such a system there also needs to be generic services such as housing, education, transport and health care. People with a disability should be able to access these services that other Australians expect as a right. In the current system, people with a disability are expected to be grateful for being treated in a segregated manner, somewhat like an apartheid system. The next area I want to speak about is the national - you want to go there? Okay. I'll hand over to Francis to finish this off.

MS SCOTT: Okay.

MS VICARY (QDN): We're doing a tag team. So basically we acknowledge that the current system is not working. We acknowledge the commission's report in really taking a hard look at it and trying to structure a system that works. I'll go through a few of the key areas that we are commenting on today, but we will be writing a full response to the draft report.

The national and portability of the system: QDN supports a national scheme that will enable people with disabilities to live anywhere in Australia and move according to their life choices and/or circumstances. A national scheme will also eliminate the current state variances that occur across disability types and diagnoses. I know as a person with a disability, and every one of our members who is in receipt of support in this state know, that they cannot seek employment or living options in any other state in Australia because they will immediately lose entitlement. I think you actually get 12 months to carry your entitlement interstate but, other than that 12 months, you go to the bottom of the authorisation pile of the state to which you move. As we say in our overview, this smacks of a segregative and apartheid-type system.

Under principles of entitlement, QDN strongly supports the NDIS, providing it remains true to the following principles and goals. People with disabilities have access to, and choice of, equitable access to supports and services across Australia. So it wouldn't matter when you acquired your disability or where you acquired it, if you required X amount of support to be in the community in which you choose to live, you will get it.

Research to identify needs that recognises local and cultural differences, including rural and remote communities and, having grown up in the Gulf country of Queensland, I know what it's like to live in a system where you get no support. One way to address that might be to have fly-in, fly-out teams, similar to the Priority Country Area Program that operated in correspondence and district education system, where people in those rural and remote communities get educational support on a regular basis, and can carry on their lives where their families and they choose to live. So there needs to be a system that focuses on people's abilities and maximises participation and in an earlier session, Patricia, you asked for independence. We actually have a view that independence is more accurately described as interdependence.

MS SCOTT: Interdependence, yes.

MS VICARY (QDN): Every one of us, disability or not, is actually dependent on a certain system of support. In a family, there's someone who does the groceries; there's someone who looks after the house. There's a whole web of interdependence. I know people with disabilities who receive support to do the things that they need to do to keep body and soul together, contribute greatly to that interdependence by having other things, like being organisers, or being a conduit between people in (indistinct) or that kind of thing. So we see as maximising abilities and participation, so that people can truly be interdependent.

Some of the supports and funding can be used to support their lives. People participate in work, leisure, creativity and cultural development. So people need choice. If a person has a structured system of support, a career that's structured times, and their local community says to them, "Hey, Bill, do you want to come to a barbecue on Saturday?" and they say, "Oh, can't possibly do that. I need to be home so I can have assistance to eat," they know that their support service will not accompany them to barbecues because the necessary risk assessment hasn't been conducted, or whatever, and that actually limits people's ability to be contributing members.

So that's really important. We strongly support people having direct control over - maybe not direct control over funding. Some people will want direct control over their funding, but most people want direct control over where and when they receive the support to which they are entitled.

Equipment: a system also needs to make a timely investment in people and their families to maximise cultural development, inclusion, skill, and negate the effects of impairment or handicap. So when someone is in school they need to have a trendy mobility aid so that they can keep up with the other kids, and they need to be able to go out with their friends when they're in high school so that they can actually be part of the system.

By having that equipment that enables them to participate, they then have access to a whole lot of informal supports which reduces over time their reliance on formal or paid support. For example, when I was a teenager I had a friend who, you know, if Lauren's in town, "Good, we'll go shopping." She was my age. She had a licence and her P-plates. She knew, when we went shopping, that she fed me and she assisted me in other areas, and that is because it was a naturally occurring support, and I was able to do that because I had a family that supported that, and I had a wheelchair that enabled me to be in the community, and that's a nice segue to technology.

Access to funding for aids and equipment, as you note in the report, is vital for many people who use assisted technology to access community work, communicate, recreate and function. As informed by the ICF and consumer input (indistinct) users prioritise these requirements can be defined as the best combination of equipment, personal care and environmental design, access to sufficient funding to pay for good quality, long-lasting equipment. Currently in Queensland, people with disabilities who require power wheelchairs - the cost of a power wheelchair can be between $10,000 and $20,000. The funding gap for power wheelchairs is between $5000 and $8000. That means that people are required to co-fund the other portion.

Some people, like myself and Nigel, are fortunate that we actually work and we can access a different source of funding, namely the Workplace Modification Scheme. So both of our mobility aids are subsidised by that scheme. However, we are more able to economically contribute than other people who don't have access to that Workplace Modification Scheme. So there is a significant poverty trap for people requiring mobility aids. Another area of importance is having their need looked at holistically so that a new piece of equipment doesn't negatively impact on your ability to do things. I've had people who get a new wheelchair and they can no longer access their computer because the wheelchair is so high they can't get under the desk. That is not useful.

MR WEBB (QDN):   I'm doing that right now. This chair I'm in today is a week old. I've had to make modifications to my public housing so that I can actually access my kitchen bench. Now I have to go into a queue with a therapist to come and do the assessment just so they can shift my bench by 40 mil. So this is what happens for people.

MS SCOTT: Yes.

MS VICARY (QDN):   And Nigel is articulate. Imagine the difficulty for someone who is not articulate. That is what we at QDN always remember; is that it's the voice of the people who maybe can't speak for themselves that we need to really be aware of; so accessing support to get the whole process right, trial, training and performance, and having your personal preference and identity considered. I really wanted a lot lighter wheelchair. This wheelchair weighs twice as much as my previous wheelchair, yet we're going backwards in terms of research and development and style and aesthetics. Those points are from a paper that I've written with Desleigh de Jonge and Natasha Layton. Desleigh is from the University of Queensland and Natasha is from Deakin University.

With regard to transport, QDN really supports the inclusion of transport in the NDOs so that people have access to affordable transport options that are delivered in a uniform manner across Australia. Some of the key points that will impact on this are the need to make serious progress towards a DDA-accessible transport centre and their implementation time frames. Currently buses in some places are travelling okay in terms of accessibility. However, there are exemptions in place, and while these exemptions remain in place, it means that those forms of public transport will continue to be inaccessible to people.

Public transport is the most affordable means of transport. This is why we really request the nationalisation and indexation of the taxi subsidy scheme to provide an affordable transport option for the most vulnerable people, those people who because of their disability cannot access public transport, or because of where they live cannot access public transport. We also support one-off funding for vehicle modifications to make vehicle ownership affordable for people with disabilities. To give a comparison, many people with disabilities or families could afford the cost of a $28,000 small to medium-sized car. They cannot afford the cost of a $60,000 to $100,000 modified vehicle.

I was horrified last year, when overseeing a project at the University of Queensland on vehicle modifications, that the average cost of a modified vehicle - just to carry a wheelchair that is, not to have the person driving the vehicle - was between $60,000 and $100,000. I immediately went home and told my partner, "You can forget it, because we'll never be able" - like, we could buy a baby Mercedes for that cost, and you can bet the modified vehicle would not be as aesthetically pleasing.

Another key area is employment. So we support the incorporation of the current disability employment services into a national framework. Three key features of such a system will need to be user choice, in terms of which service people want to use - and I say this because I have a degree in literature and a masters in literature and journalism and I have never found a disability-specific employment service useful or to achieve an outcome. I have had the most positive outcomes from a generic employment service and a national one, like Sarina Russo, and yet currently to access workplace personal care I have to actually sign up with a disability employment service. I'm lucky that in Queensland we have one - well, we have others but the one that I've chosen has a relatively good values base and looks at the person's skills and independence.

I think Nigel will be able to support this. Some job development officers who have spoken to us in the past have been intimidated by our level of skill and have even sunk to patronising us: "Oh, you're so wonderful. Oh, you know so much," and yet 12 months later they still haven't found us a job.

MR WEBB (QDN): And if they do, it might only be entry employment opportunities rather than opportunities that match your academic or life experience skills.

MS VICARY (QDN): I think there really needs to be a matching of people to employment services. It's a big choice. Just because you need workplace personal care you shouldn't need to sign up to a disability employment service, which you currently do.

Moving on to implementation, QDN is supportive of most of the proposed structure. Concerns arise in the lack of adequate data upon which you base costings and the need for this system to allow for volunteer nursing as a solution to ensure that the needs are all met. We struggle in terms of data collection and research because we know that we don't know; that is the key thing. There should be a quarantined fund for an independent research and data collection branch. In the report you recommend they're sitting under the NDIA. Our concern is that significant funds will go into this research and data collection because of the dearth of any coordinated national research, and that this will seriously impact upon the ability of the scheme to deliver support services. So it's mainly a funding scheme.

We know there's a lack of evidence. We know that there needs to be research into unmet and undermet need because many of our members - we have over 850 across the state - receive support but do not receive support to do what they would like to do.

MS SCOTT: Francis, how much more have you got of your presentation?

MS VICARY (QDN): That's it.

MS SCOTT: Well, there we go. I was conscious that we're running out of time and we do want to ask some questions.

MS VICARY (QDN): That's it.

MS SCOTT: John, do you want to lead off on the questions? I'd like to ask quite a few questions about the data material, but you may want to start there.

MR WALSH: My only question, Fran and Nigel, is that you haven't mentioned anything about accommodation options, particularly supported accommodation options. Do you have any position on those sorts of models?

MS VICARY (QDN): We had a fairly high-order position that people with disabilities should be able to choose where and with whom they live. We know that the current system forces people into co-tenancy and QDN is actually part of a group that opposes forced co-tenancy. We are fully aware that some people may choose to share supports and to live together. However, our position is that these should be options for people to live where and with whomever.

I note with interest, John, in the report where you talk about the ability to cash out a section to do home modifications and all that kind of thing. We know that when people are working and purchase houses, as you do when you work, that the cost of modifications is in the range of between five and 50 thousand dollars and that is currently funded by the person out of their own pocket, which leads in the long term to a reduction in their superannuation and has a negative impact on their overall economic position. So our view would be that there needs to be funding for a range of housing options. Social housing needs to be made accessible and conform to universal design standards and that kind of thing.

MS SCOTT: John, I've got a question about data.

MR WALSH: Yes, go ahead, Patricia.

MS SCOTT: Thank you. Francis, you suggested that research and data collection should be separate from the NDIA. I'm just conscious that because we envisage the scheme being an insurance-style scheme and that it requires information backwards and forwards in terms of what services are available, what services are taken up, what assessments are occurring and so on - and obviously cost control and quality control - that data would be absolutely key to the success of the organisation. So could you talk about that and how you see research and data collection being separate. Is it just a matter of - - -

MS VICARY (QDN): Well, I think I need to clarify. I fully understand that the NDIA will need to do research and data collection so that they know what the need is, they know what the coming needs might be. They can have both estimates and that kind of thing. What we're talking about is higher order research into things like ways to improve social inclusion, into design of wheelchairs, into preferred model of support, that kind of thing.

MS SCOTT: Okay.

MS VICARY (QDN): We don't - but to fill that gap of research outwards, taking money from a fund that needs to be primarily for delivering direct support.

MS SCOTT: That's fine. Nigel?

MR WEBB (QDN): That largely comes about because of the lack of information that's available around what it costs to deliver the services. If you say as a whole, "I'm going to do some research over here," then there's a tension in your budget areas between, "If I've got to do a $5 million research project on X and then I've also got to deliver $50 million worth of services," it's like - so we want to be able to have some quarantined resources to say that research happens independently of the way in which we drive the model for the people of higher end resources and making their application for available resources.

MS SCOTT: So your primary concern there is that other demands for the individual's needs will sort of gobble up the research dollar, if it's not specially quarantined off.

MS VICARY (QDN): Yes.

MS SCOTT: That's right?

MR WEBB (QDN): Or the other way around.

MS VICARY (QDN): Or the other way - - -

MS SCOTT: All right. Fine.

MR WEBB (QDN): Because at the moment we don't have enough data to say what's happening nationally. We have a lot of information that's collected by the Commonwealth that comes from the states but everybody - we're not talking apples with apples. We've got apples, oranges and bananas all mixed in together. I'm sure you understand that well.

MS SCOTT: We've had data problems as well.

MR WEBB (QDN): I just don't want to create a fruit salad that people can't navigate. So we've got to be able to work well because the end dollar has got to go to the person who needs it.

MS SCOTT: Yes, that's right. John, any further questions for Francis or Nigel?

MR WALSH: No, that was excellent.

MS SCOTT: Janelle, is there something you'd like to say?

MS TONG: No.

MS SCOTT: No? All right. I just wanted to confirm one point. Francis, you were directed to a disability employment service.

MS VICARY (QDN): Yes.

MS SCOTT: But you in fact - if I've got the gist of it - would have much preferred, given your experience, to actually go off to a generic service.

MS VICARY (QDN): I was directed, for instance, to an employment service by Centrelink when I went to Brisbane in 1999. I worked at that service for about four years until I went to Centrelink in a degree of frustration and demanded to be redirected to the local Sarina Russo in my area. Six months later I had a job.

MS SCOTT: Okay. That's one thing we might explore in terms of the detail of - - -

MS VICARY (QDN): I really think for people with a certain skill set, the disability employment services are not always meeting their needs.

MS SCOTT: Yes. And, Nigel, you would concur on that point.

MR WEBB (QDN): Absolutely. I've been very involved in the employment sector. In another role, I'm a technical expert for the quality assurance scheme so I actually interview people with disabilities all the time as part of my work, and provide feedback through the quality assurance. The feedback we have is that, yes, they provide some specialist skills at one level and, yes, you could contract that specialist skill in, but also for people who are acquiring necessary skills to compete in the workforce, tertiary qualifications and the like, then you need to be able to go out and test your skills or your education in the marketplace. So access to a generic service is probably better positioned to do some of that because of their particular expertise or knowledge within the community in which they choose to operate.

MS SCOTT: Gotcha.

MR WEBB (QDN): And establishing those good business relationships, so Interacts has got a very good track record of being able to do that, and there are other examples. But I would support the notion that there are people with disabilities who would need the specialist service delivery, so if you could broker that in, almost, and say, "Well, okay, I'll buy in so many hours of specialist service to get me under way," or to educate a generic service to say, "These are the sorts of supports Nigel will need initially to get started, or progressively over time to be able to advance the career prospects and career opportunities to fully participate in the workforce."

MS SCOTT: Can I go back, Francis, to something that you started off with, which was about interdependence - - -

MS VICARY (QDN): Yes.

MS SCOTT: - - - rather than independence. I want to challenge you a little bit, but respectfully. I did see some appeal in Angela Tillmanns' presentation because it was about a community invests in the individual and the individual can set small or large goals and there's effectively a pay-off for that individual from that investment.

MS VICARY (QDN): Yes.

MS SCOTT: So that independence, achieving a greater level of independence, is probably quite a natural desire that most people have. You've stressed the interdependence we have in our society. Do you find the independence argument that she suggested problematic? Do you find it insensitive? What's a concern that you might have about that?

MS VICARY (QDN): No, I don't find it problematic or insensitive. I think that we're actually talking about the same thing. It's just that I think that if a community is supporting a person to do something and then they (indistinct) it and delegate it -

that is what I understand, as in her opinions, in that no one of us is fully independent.

MS SCOTT: Okay. So because we're interdependent, we get to then exercise more independence.

MS VICARY (QDN): Yes. And then when we have a system that actually supports people to be in turn - supports their interdependence by having personal care assistants or assisted technology or whatever, then people can actually contribute and be genuinely part of community and can give back.

MS SCOTT: That's good. That's very clear. John, do you have any further questions for Nigel or Francis?

MR WALSH: No, thanks, guys.

MS SCOTT: Thank you very much for your time. Thanks, Janelle.

MS VICARY (QDN): And we will be doing a form 76.

MS SCOTT: Yes, good. Thank you. And all by 30 April. No, don't laugh.

MS VICARY (QDN): Actually before Easter because I'm going on leave.

MS SCOTT: All right, even better. That sets the challenge for everyone else. Very good. Thank you very much.

MS SCOTT: I welcome to the table John Homan. John, for the record, could you indicate the organisation you're representing today, please.

MR HOMAN (CCDAI): I'm John Homan. I'm Amanda's father, and I represent Capricorn Community Development Association in Rockhampton.

MS SCOTT: Thank you for coming here today and we've assigned 25 minutes to your presentation and discussion.

MR HOMAN (CCDAI): Thank you. I would like to make an observation here. I don't have any barrows to push any more because my daughter Amanda will not benefit from any reforms. She died on 9 January.

MS SCOTT: Our condolences.

MR HOMAN (CCDAI): What I want to do too is recognise the Jagera and the Turrbal people who are the traditional owners of this land, and elders past and present.

I looked at the report with a great deal of goodwill and hope. There are some things in there, though, that I believe are wrong. There are two issues specifically I wish to speak about today. There doesn't seem to be a clear vision where the NDIA is going to go and that means that we don't really start with an end in mind. The end in mind to me, and I think Maslow had that right, was that every man should become what he can be. That to me means that everybody should be on a journey to his potential.

Now, as waypoints on that journey are self-awareness and also empowerment. For people with disabilities that's an awful lot harder than it is for the rest of us, not just because of their disability but also because of the roadblocks that we as a society put in their way, one of which is the charity model of disability which does not allow people to own their own lives. If that is the light on the hill for the NDIA as well and it's not spelt out, then we have a choice in two types of organisations: one hierarchical one where old power and knowledge is vested at the top and the people at the bottom are basically messengers. If that is the case then I would say that the NDIA will fail because that is the system that we've suffered for centuries.

The other one is a collaborative system where we turn the organisational pyramid upside down and the people at the coalface are at the top. They're the ones that we empower and support form the bottom up. If we run a system like that then we have a chance. This is not a matter of necessarily reinventing the wheel because in actual fact that's how the west was won. Western Australia in 1988 stepped right out of the box and invented local area coordination. They didn't invent it in the city;

they invented it in the country. So that answers a lot of questions about how does this system work outside the metropolitan areas. From Albany, where it started, it has developed over the last 20-odd years. It is now throughout Western Australia and to me it ticks all the boxes as to where we want to go, and I just want to read you their charter, which is in here:

> The charter of local area coordination is to develop partnerships within individuals and families as they build and pursue their goals and dreams for a good life and with local communities to strengthen their capacity to include people with disabilities as valued citizens.

To me it doesn't get better than that. They don't mention empowerment, which is interesting, nor do they mention money in this. The interesting thing there is that they don't mention it because it's not part of their core business. Their core business is what the title says. But in 2000, Angus Buchanan, a professor in Western Australia at the Curtin University, did a study on whether people that had funding were more empowered than people that did not get funding.

The surprise to Buchanan, but not to local area coordination and Eddie Bartnik, was that he couldn't tell the difference. He put that down to the fact that all the people that were in the study had access to local area coordination and it was the relationship stuff that empowered them. So what I'm basically suggesting is that we don't invent a new system but that we go to Western Australia and adopt the West Australian system and we propagate that to communities across the Nullarbor.

A few things bothered me in the report. One was that there was a line there that assessors - which is an ugly word to me; sounds like taxation - are to be trained not to give soft or hard analysis. To me that's sort of hierarchical and bureaucratic in its nature. The other one that really bothered me was that it said somewhere along the line that assessors should not have had previous relationships with people that they deal with. That is in total conflict with what we know works for empowering people and getting people's self-awareness up, because that is a process of peers mentoring and teaching each other. We all learn best from the people we respect and that we have a collaboration with and a relationship, rather than the people that come and tell us what to do.

So they worry me that they are in the report because to me that's in actual fact - they're pointers towards a hierarchical type of system. I prefer a system that is not code ethics based and risk averse, as departments and a lot of organisations are. I like to see a system that takes risks, manages risks and with that is innovative and builds relationships. So that was my first major concern.

My second major concern is that the complaints mechanism is built within the

NDIA. Now, people with disabilities have suffered that sort of internal investigation system in organisations for decades and longer and are very suspicious of it. I think if that should happen, no matter how credible the system is, the mere fact that it's embedded in your organisation will basically be damaging to the NDIA. I would like to see an independent system, as I put in both submissions; a system that's independent of the NDIS and the NDIA. Also, there is some evidence that the higher we set the standard of proof, the more likely people that are guilty will get off. It was evidence in the trial of the terrorists in Sydney recently where two got convicted; the other two did not get convicted because of lack of evidence.

So when we're looking at people that are vulnerable then I believe that the standard of proof should be commensurate with the differential in power between the person that's making the complaint and the person that's being complained about. There's a fair bit of literature on that and you asked for it earlier, Patricia. That was in my submission. There was one thing that I wanted to draw attention to, and that is there was an inquiry in the United States, what they call the Kerr/Haslam Inquiry, and that was sexual abuse in a psychiatric organisation. The guy who worked there and later became the head of the organisation wrote a comment on the inquiry - a guy called Peter Kennedy - and what he had to say is quite interesting. He says:

> The level of allowable evidence will bear on the likelihood of getting a correct decision, hence a wrong outcome for very vulnerable people will be most damaging. The required level of proof for them should be lowest.

And Peter Kennedy, commenting on the Kerr/Haslam Inquiry into Sexual Abuse, said:

> The report recognises that rumour and gossip can be grossly misleading. Perhaps 2 per cent are false. However, when rumour, gossip and withdrawn or unsubstantiated allegations refer to the same person repeatedly, the balance of probability grows that patients are being harmed.

So there are two reasons why I think we need to look at this as part of the system, because we have to restore the balance. In a normal case people have roughly equal amounts to lose. Where there are vulnerable people then there is a differential. The person that is more vulnerable has more to lose. A Sporting Wheelie who is only partially dependent has less to lose and is less vulnerable than say somebody with quadriplegia and no speech and that is dependent for everything in their lives. They're highly dependent and consequently highly vulnerable. I'd have to say now what is the effect if the person gets on either one? You'd have to then say the person that is the Sporting Wheelie can demand a higher standard of evidence than the person that is highly vulnerable.

The other thing that I believe that we are not doing right and have not been doing right for a long time is that the focus largely, in complaints, is on the defendant. We're always looking after the defendant first and making sure that his rights are met, and all that sort of stuff. The person that is abused is actually not even a sideshow, with the result that you can have, say, a case where there's an accusation of abuse. In the old system, the person will stay in the job until proven guilty, which can take 12 months or two years, which means that the vulnerable person will remain vulnerable to this person for all that time.

I think that the saying "Better to have 12 guilty men go free than one innocent man convicted" should be turned around. I believe that we need to put the safety and the wellbeing of the disabled person, the vulnerable person, first before we start looking at punishing the guilty. That means, in an incidence of abuse, removing this person from the job so that they cannot inflict further abuse.

Another thing that I highlighted in my first submission was that, particularly with people with intellectual disabilities that only have one care attendant at the time, their evidence is not credible, usually, and they really need to be very lucky for all the stars to be in alignment; that there is a person visiting that recognises the abuse; that is prepared to make a complaint and is prepared to make a complaint in writing. This means that abuse can go on for a long time, and I think we need to take account of that. So they are the main complaints.

I said I wasn't pushing a barrow. I am pushing a barrow and I'm pushing a barrow for a good system. I believe that unless we have a system consistent with what I've outlined for complaints management, the NDIA and the NDIS could fail because of lack of oversight. I believe that we need to create a culture where complaining is not only natural but it should be applauded because it's looked upon as a learning experience rather than being punished, and it's a way to improve the organisation. Some organisations do this, actually.

One of the other things that I've highlighted in my submission that I wasn't happy with is group homes. I believe that group homes should only be a last resort, because frequently we get people to live together that should not be living together. Rhonda Galbally made some comments on that in her Shut Out report, and I subscribe to those.

There's another problem, particularly with intellectually disabled people - and I have experience of that - and that is, if you put a smart person in with dumb people, or people of little capacity, then the person with the skills will dumb down, which again is a waste of talent and getting away from our light on the hill and that is to work towards empowerment.

Another thing that I commented on was training. There is a para in the report - I'm on the wrong page, aren't I?

MS SCOTT: I think it's on page 10 of your submission.

MR HOMAN (CCDAI): Is it? Thank you. There is a para that says that doesn't want to put an onus on training and rely on people's good intention and communication skills and citizenship. To me, they are the things that are the value base that is not negotiable. Beyond that, I think they can do an awful lot of harm if they don't have proper mentoring, training or both. Training, to me, is about knowledge. Mentoring is about understanding. So I think people need both, from a point of view of risk management, from a point of view of what the boundaries are in the relationships.

I think I probably mentioned another couple there, but I think these are important things that we need to keep in mind. Plus the fact that the community services sector as a whole, which I deal in now through community development, has worked very hard to raise its profile. They had a profile of being glorified maids and they now are trying to raise themselves to a professional level, which they have done to a large extent, which also improves their recruiting standards and gives them a chance to get better staff, more dedicated staff.

I think also that not having trained people could be an impediment to recruiting and may exacerbate work shortages. A nurse I knew used to say, "Back to the days of Sarah Gamp," who was a nurse in Dickens's Martin Chuzzlewit, who was drunk on the job, rude, profiteering, and I think we have that chance if we don't train people properly.

MS SCOTT: Thank you, John. Now, John - - -

MR HOMAN (CCDAI): I just want to mention mental health. I think mental health, because of what John Pini pointed out in Canberra last year, for one, where so many people with disabilities have dual diagnoses - it needs to be in as a disability, but also, I think, so that we can treat the person as a whole rather than do it on a silo basis, between mental health and the health departments. I think it's terribly important that we recognise that.

MS SCOTT: What about a person who only has a mental health issue?

MR HOMAN (CCDAI): There's a clinical aspect to it; there is a social aspect to it. I believe that the NDIS should address the social aspect.

MS SCOTT: John in Sydney, any questions?

MR WALSH: Thanks very much, John. Just one, really. That was all very clear. The research on empowerment, where it was found that empowerment in an environment of local area coordination ranged between people who received a funding package and those who didn't, can we draw from that conclusion that the right sort of framework might be able to be provided for a lot less funding than what we're proposing in this system?

MR HOMAN (CCDAI): Eddie Bartnik, in the chapter in the book on co-production and coordination in the services sector, his title says it's not just about the money. The money is important, but he also warns that, with local area coordinations, they shouldn't have to spend too much time on the funding because it would take them away from the real job, which is community. The proof on statistics, on the costs, finds that local area coordination, at worst, is equal in cost to other services; at best, can be 30 per cent better. Does that answer your question, John?

MR WALSH: That's useful, and I think you've given us that reference in your submission?

MR HOMAN (CCDAI): I have.

MR WALSH: Thank you.

MS SCOTT: John, you would have seen from the report that we obviously borrow on the idea of the local area coordination.

MR HOMAN (CCDAI): Yes.

MS SCOTT: I think we might have changed the name to "local area case managers". But is there a way in the report that we're using that concept and design that you find troubling?

MR HOMAN (CCDAI): The report didn't make clear what the design was going to be. That I found troubling. If it had said straightaway, "We're going to run it like a government department," I would probably have gone home and cried. If it had been indicated that it would be a system with firewalls, so that we get away from the risk aversion which is common in departments and get into a system that is more like real life, where we do take risks, we all take risks and we manage the risks, then I would have applauded and lit a candle. So the fact that it wasn't clear made me want to stress it here - and in my submission - how important it is that we have an organisation whose primary goal is to build trusting and lasting relationships, so that in the relationships, people for the NDIA are facilitators; they facilitate but never control.

In other words, it can be an across the kitchen table conversation about what they aspire to in their life, what can be done, how can we come to a compromise on this that makes everybody happy, and we're looking for win-win situations there, rather than people being told, "This is what you can have. Take or leave it," which is what has been going on for a long time. Again, it's about people owning their own lives for a change, being in charge of their own lives, and I think that by working a system like the local area coordination we can achieve that.

Professor Buchanan's research really proved that to me. That was really the game-breaker for me. What Eddie says - okay, Eddie may have a conflict of interest, although I don't think so - but Buchanan came in there with a different expectation, and I think that that came to him as a surprise is significant.

MS SCOTT: You also suggest that we need to reconsider the position on assessments being done arm's-length from existing service providers. You may have heard the response from the Australian Physiotherapy Association. Clearly, we've had evidence from overseas of overservicing when the service provider is also the assessor. I don't know if you heard that conversation.

MR HOMAN (CCDAI): No, I didn't hear the conversation, but I agree that there is a conflict of interest.

MS SCOTT: Yes, okay. So the way you overcome that concern about conflict of interest?

MR HOMAN (CCDAI): I haven't had a great deal to say about service providers, because I think that if they don't change they won't be there so they won't be relevant. But if we have what I suggested in my first submission, where we take the hierarchal pyramid or funder at the top, the service provider as the gatekeeper in the middle, and the client at the bottom without a say over their own life - if you take that apart and put it on the one level playing field so we have a triangular relationship, then I believe that the facilitator, in conjunction with other people and the service providers, can then cobble up something that's credible, that's sustainable, and is not a misuse of money.

MS SCOTT: All right. John, do you have any further questions for John?

MR WALSH: Just really on the same point, Patricia. John, I think the point I heard you getting at was that what you heard our report saying was that the assessor shouldn't have a past relationship with the person they're assessing, and you disagree with that.

MR HOMAN (CCDAI): Absolutely.

MR WALSH: The assessment process is a cooperative way of presenting the life goals of the person with the disability. Is that right?

MR HOMAN (CCDAI): You've probably seen what I included last time in my submission and this time, and that is a scale by Bramston Training on the difference between personal relationships and professional relationships. That is entirely sustainable provided we employ the right people. This is what Eddie also has to say in the chapter that's in the book and that he sent me, that the system is only as good as the local area coordinator you've got. So I think it's entirely practical for people that are local coordinators - and it's happening, it's a system that's proved itself over 20-odd years, with plenty of reviews and oversight and all that sort of stuff - for a person to have a personal as well as a professional relationship, as long as they understand the boundaries. It's the same with support workers, and that is one of the things that they need to learn before they're let loose on a client: what are the boundaries of these relationships? Does that answer your question?

MR WALSH: Yes, it does. I understand. So I guess what the commission needs to try and still maintain is the integrity of the funding allocation.

MR HOMAN (CCDAI): Yes.

MR WALSH: So we do need some benchmarks around equitable funding allocation for different types of people across different parts of Australia. So you'd be comfortable still with that being an objective process?

MR HOMAN (CCDAI): Up to a point. I think that people in different situations or in different localities or with different characteristics may have different wishes or dreams and I think we need to take that into account. It can't be a one size fits all. It needs to take into account what is best for the person and what the person feels is best for them. I remember In Control, I think it was, mentioned this guy who wanted to join a singles group because he felt socially isolated, and that was allowed because it was a genuine result of his disability that could be corrected. So I think that it needs to have that flexibility.

I remember John Pini - you may remember him from Canberra. He was here last time I presented - from UniCare. We had a new minister. He was regional director in Central Queensland at that time for DSQ, and the new minister asked him, "What are you actually doing here, John?" and his answer was, "We try and make a difference and to do it we take risks." Now, he could have dressed it up and he could have said, "We innovate," but it's exactly the same thing. So it's a matter of taking risks, but managing the risks. I think the same applies with whatever you call them, assessors or facilitators. They have to be prepared to step outside the box to get best outcomes, but manage the risk. I've learnt over the years that you don't always have to be right, but you have to be able to defend your decision.

MS SCOTT: True. John, something you didn't discuss today, but I see from your submission to us, is that you support the Medicare system of funding. One of the issues that we identify in the report is that there may be drawbacks to that arrangement, because the Medicare levy only covers a very small proportion of the total costs of the health system - so if it was truly a replication it would only cover the small cost of disability services, number 1. Number 2, there are exclusions from the Medicare levy, including people in Defence for example.

MR HOMAN (CCDAI): Yes.

MS SCOTT: And number 3, the design of the Medicare levy at the moment is such that you end up with actual poverty traps because, because of the exemptions, you suddenly have to bear the levy and you end up with very high tax rates. So we actually recommended, if the governments were interested in that, an income levy, but, better still, that it be financed from general revenue; in other words, that the funding be set aside from general revenue through a formula arrangement rather than a nominated levy - so you don't have a nominated levy for defence, you don't have a nominated levy for social security, you don't have a nominated levy for other services that governments provide, and why did it need to have a nominated levy for disability? Did you find that persuasive? I just see that, given that you've had a chance to look at the report, you seem to be still supporting a Medicare - - -

MR HOMAN (CCDAI): I'm not sure. Did I make a comment on it in this submission?

MS SCOTT: Yes.

MR HOMAN (CCDAI): I did in the previous one. I thought I had refrained from making one, commissioner, because I'm not an economist.

MS SCOTT: Okay, maybe we attached the old submission to your new one.

MR HOMAN (CCDAI): Okay.

MS SCOTT: But in this one it's point 10, "A Medicare system of funding with capacity to vary the rate to meet cost variations".

MR HOMAN (CCDAI): The reason I like the Medicare system was that it had enormous popular support when it was brought in 20-odd years ago and I think that one of the reasons was that it was narrowly focused and didn't sort of disappear in overseas trips or ships that rust. Also I think it gave people a sense of ownership and I think that's important. So even if there was an addition to the Medicare levy, relatively tokenistic, I think that would be popular.

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

MR HOMAN (CCDAI): My pleasure.

MS SCOTT: John, are you all right for finishing now?

MR WALSH: Thank you, John.

MR HOMAN (CCDAI): Thank you.

MS SCOTT: Do we have Margaret Ward and Ric Thompson available? Thank you.

MS WARD (BS): I'm sorry, Ric is in Townsville and sends his apologies.

MS SCOTT: That's fine. Margaret, we changed the schedule unbeknownst to you but that's okay. We'll make sure that you have your full allotted time.

MS WARD (BS): When would you like me to be complete by?

MS SCOTT: We'd like you to have half an hour but we would like you to leave some time for questions from John and I. It's right on 12.00 now, so by 12.30 we'd like to wrap up. So welcome to the public hearings. Would you like to make an opening statement?

MS WARD (BS): Thank you, commissioners. I would like to open my presentation by applauding the report. We believe that in relation to our presentation - that is the Blue Skies scenario, for the people here - that we asked for four things and we believe that you have provided those. One is adequate, timely and appropriate support for people with disability, increased empowerment, a capacity or a strengthening of a capacity for people to contribute to society through valued roles, and an opportunity to maintain and strengthen meaningful relationships.

We did offer five points on how we believed this initiative could avoid blowout and I'd like to just talk to two of those because we did not feel they were addressed. I'd like to preface what I have to say. I'm not convinced that it is your purview to do this. Nevertheless, I do bring these to your attention because any initiative that avoids blowout would be of interest to you.

MS SCOTT: Thank you.

MS WARD (BS): The two points do follow very closely the presentation by the former gentleman, John, so this is timely. One is that we need some understanding and response around the capacity-building to assist communities to include people with disability and welcome their participation. The second is the capacity-building of people with disability to not only plan but to envision a good life for themselves and to plan for the future and to build that good life. I'd like to talk about number 2 first and then the second one follows.

I think John's support for the LAC program is because - and I hope this is okay for me to say this - these two strategies are addressed through the LAC program. Most families and people with disability, if they acquire a disability beforehand, most probably have the attitudes common to society generally before disability comes into their lives. Typically society now does not have high expectations; that is, to work, to marry, to live a full and fulfilled life. So I don't think we can expect an epiphany with families when they may have a child with a disability or that people who acquire a disability necessarily have significantly changed attitudes either.

However, families have been seen to be, over the years, the most robust mechanism to keep a vision of a good life for the person with disability and to hand that down from one generation to the next. I say it takes three generations to support and protect and safeguard a person with a disability. First that is loving family, loving parents, then often siblings and good friends. And then, as the person ages and becomes even more vulnerable, it is the next generation of the children of siblings and friends that watch out for that person. So we sometimes stop at parents but if we look at the whole cycle of life, this is a long-term strategy to hand down a vision, to continue the planning and revisit that vision and plan throughout that person's life.

Typically, systems don't do this and certainly service providers aren't there to do this, particularly now that we have at present a 20 per cent turnover of staff, so any real understanding or I guess corporate knowledge of the person is lost within five years. So we go back to that capacity-building of people with disabilities and their families to envision what is possible and then to build a good life. It is what Blue Skies and those organisations that do this work call a way of thinking: to envision, plan, build, envision, plan, build, and that is an ongoing process.

Now, I'm talking here that if this is in place - not always but often - service takes a very secondary role because there is a way here or an ongoing strategy to really be very clear about what the needs are and to have the involvement of a very strong network of support of informal people. When we find that we're doing this work with families to build a good life - to envision, plan and build - the discussions around service are typically secondary. While I'm saying that I'm not sure whether this is actually the work of the NDIS, if this work is not done then I think the NDIS will have repercussions of having to spend more money than they need to.

The second one is the capacity-building around communities and that is that here the local community is the client, not the person with the disability. What we need aligned with the NDIS are very intentional strategies to assist communities to welcome people with disability.

MS SCOTT: Sorry, Margaret, I just got confused there. I just want to clarify because I think you might speak a bit more about that. Could you talk about the difference between the client and the person with a disability? Can you clarify that a bit more?

MS WARD (BS): I'm using that in a - any strategy for community building is focused on the community rather than on the person with the disability.

MS SCOTT: Right, okay. Sorry.

MS WARD (BS): That's fine.

MS SCOTT: That's clear, thank you.

MS WARD (BS): The goal would be to assist the community to welcome people rather than ask the person with disability to change. I raise these two for your comment because again, as I said before, I think without intentional strategies in those two areas, the NDIS may in fact - with all their efforts to empower people - be spending more money than they need and not be meeting their goals about increased empowerment and their contribution to society through valued roles.

MS SCOTT: Okay. Thank you. John, do you want to lead off?

MR WALSH: I think what you've presented, Margaret, is certainly important to what we say. I'd like you to talk a bit about - and I think it's entirely consistent with where we would like the NDIS to go. Could you talk a bit about the challenge of this and, in a practical way, about achieving this outcome. You talk about three generations, but if we can narrow that down to maybe three years, what would you aim to achieve in three years and how would you go about doing it? Particularly, I think, we've heard a lot about local area coordination, and that started out in rural areas predominantly and moved into urban areas. How would you do this in large urban situations, bearing in mind that probably 80 per cent of the client base that we're talking about, people with disabilities, live in big cities?

MS WARD (BS): Thank you. I'd just like to preface by saying working with families particularly is a messy business and the state of the art of this work has not been reached in Australia. There are exemplars around. I can name two in Queensland, one being Pave The Way organisation through Mamre Association, around working with families to envisage, plan and build, the other being the Community Connection work in North Queensland. We can send you those references. The Community Connection organisation in Queensland, in Townsville, is an exemplar, we believe, of the work around capacity-building within communities.

If I go to the first one there: number 1, as John said, it's about relationships, because you're asking families to change their ways - in fact, actually to work counterintuitively to how Australians normally do things; that is, to envisage, plan and build. Typically Australians don't plan this very well. We know this from our superannuation dilemmas. Secondly, it is about bringing in, in an intentional way, networks of support through families, friends, neighbours and community. This is not a common practice in Australia. We do have a sense of being self-sufficient and keeping our family lives private.

Nevertheless, families who have a person with a disability, and a person with a disability themselves, sometimes have problems and challenges that are bigger than them and bigger than them to deal with, and a robust and well-practised strategy - certainly overseas and becoming more frequent here - is to intentionally build networks of support. So it is a messy business. It is counterintuitive to the Australian way of life. Nevertheless, it has been found to be one of the most robust strategies for families to move from surviving to thriving and to develop very good visions and plans and to be able to build a good future for their family member.

MS SCOTT: Margaret, I wonder if I could interrupt here, if that's all right? In some ways, when we were here last time - and I remember your testimony last time - we spent much of the time on waiting lists and the difficulty of finding attendant carers and lack of choice and so on. So you can see any number of those things have been picked up. I guess what you're drawing our attention to is that we don't spend a lot of time on this - you know, the role of the community in the work - and we certainly could spend more time on it. But I'm interested in asking you a question about whether that's the right role of government.

You've made the point a couple of times that this could be more cost-effective than other approaches, but if the NDIA is about early intervention therapies and about wheelchairs, about aids and appliances, about hopefully getting people into work, providing a greater level of independence, some of the things that came through this morning, where is the role of the government in making the link-up with community groups? Where does the government's job start and where does it finish?

I guess that will depend upon each person's circumstance, but one of the people providing testimony to us in Hobart said - and I think to my surprise - "One of the troubles with a proposal for a well-funded scheme is it will mean less fundraising, less charity work and, therefore, less community participation." So could you just talk about this difficult issue of where does the role of government start and finish? What role does the individual play, and family and Rotary clubs and Lions and your own association and the work of Pave the Way, for example? Does everything have to be incorporated within the scheme, or can the local case manager simply say to the family and to the individual, "Fred, if you're thinking about your future prospects, maybe you would benefit from being in touch with this group"?

MS WARD (BS):   What I'm talking about is a capacity to assist families to do this work. An outcome would be that when the case manager comes, the family says, "This is our vision. This is our plan. This is the bit we want you to do. We're cool on the rest, because we've got it sorted."

MS SCOTT: Right, okay.

MS WARD (BS):   Okay?

MS SCOTT: Yes.

MS WARD (BS):   "And in fact it's not really your business, okay. So we know where we're going, we know the sort of life we want for our family member. We are clear. Not only are we clear, but we've got the next generation being clear and the next generation being clear," and in brackets, "because we understand that what gives people a good life is to love and to be loved and also that what keeps people safe is other people who love you in your life."

So that work is done already by families, and when the caseworker comes to assess for the NDIS their job is really quite clear and the purview is clear. So when that work is not done, the case manager comes and sees a whole lot of issues that aren't addressed, that they're not coming as partnerships, they're coming to offer a solution to people who feel very disempowered and lost in a society that doesn't care, that is not particular interested - or appears that way.

So it's this fundamental work that needs to be done alongside the NDIS that is going to make the NDIS have an easier job. Whether that's funded by government or by Rotary or whatever, I'm ambivalent about. Certainly there's a whole argument for a variety of funding sources, but that's not my point. The point is that this work needs to be done, it needs to be intentional, because it is counterintuitive to the way normally things happen for people, particularly for people with disability.

MS SCOTT: Okay.

MS WARD (BS):   And I'd just like to add, it's very cost-effective. It's around $2000 a person a year, $50 a week, if you were to do this work.

MS SCOTT: John, do you have further questions for Marg?

MR WALSH: I'd like you to clarify that costing a little bit, Margaret.: $2000 per what sort of person?

MS WARD (BS):   If you take the family who comes and says, "Can you help us build, to get a vision, to think through how to go forward?" there may be some intensive work to start with that family, to give them some ideas, to show them how to invite people into their lives, how to think about the importance of planning, and that's a matter of conversations, and have some workshops; perhaps even taking the family away for a while so they can think through the issues that they have. Then, over time, once the family gets it and understands what they need to do, that support pulls away. It's a very arbitrary figure, but I guess I'm trying to illustrate to you that it's actually very cheap.

MR WALSH: Have you had a look at all in our report about the proposed role of disability support organisations?

MS WARD (BS): Yes.

MR WALSH: Do you envisage that perhaps that sort of structure could facilitate this role?

MS WARD (BS): I think it's separate, because the capacity-building of community really needs to be separate from a disability service. It's a notion. I mean, a lot of this work has been done reasonably badly through community development workers in local government authorities. I'm not advocating that that's where it should be, but it's about assisting, being present in a community, understanding the opportunities within a community, and assisting those opportunities and individuals within the community to be more welcoming and receptive to people with disability.

MR WALSH: I don't see how it's inconsistent with our view of disability support organisations.

MS WARD (BS): Okay.

MR WALSH: And not service providers, by the way. The proposal is that disability support organisations would not be service providers. They would provide this sort of support role for families, to help them plan, as people with disability. Perhaps you could have a look at what the report says about disability support organisations and come back to us with some thoughts on that.

MS WARD (BS): Okay. I most probably misinterpreted it, then. My understanding when I read it was that it was focusing on a service response. What I'm saying is that, before that, there needs to be some very significant vision building and networking, showing the family how to network, envision for themselves, plan and build, and that service may in fact be a very small part of that.

MR WALSH: I don't have a problem with that.

MS WARD (BS): There isn't the assumption that the answer is service.

MR WALSH: No. If you could maybe assist us to clarify how we might structure that in the report, that would be useful.

MS WARD (BS): I'll just give you an example. In Queensland in the mid-90s there was a very innovative program called - Post School Options, I think it was called then. Its name has changed. It was cash, not necessarily directly to the family but that could be used in a number of ways to assist the young person leaving school to try new things.

Overwhelmingly, families bought places in activity therapy centres and sheltered workshops. There were only a very few families who thought creatively about different ways in which their family member could participate and contribute to their local community, get work, try new ideas for adult living. I guess, in reflection of that experience, that even when families had the opportunity to plan, because they didn't have a strong vision of what was possible, they went to what was offered.

MR WALSH: Do you have that as a reference or a case study that you could send to us?

MS WARD (BS): I don't have it on hand but I can go to Disability Services and get that for you.

MR WALSH: That will be useful. Thank you.

MS SCOTT: While I've been listening to you, Margaret, I've been trying to go back to the relevant section of the draft report. It's interesting, John, I thought we had this theme through there but it's fairly light-on. It talks about shifting the emphasis towards wellness, in chapter 5, and it talks about the current arrangement fail:

> ... to systematically explore "what might be". Opportunities for improving independence or functioning are not systematically assessed on either an individual ... level.

Then it goes on to say, you know, "opportunities for people to learn or relearn skills". Then it talks about different schemes that are operated in different places, about people thinking about planning and so on, but it doesn't bring it together very nicely. I think it might be a case that we've unfortunately hidden it in the text, John, rather than drawn it out, as Margaret suggests.

MR WALSH: I'm very happy to have a look at that.

MS SCOTT: You might want to look at page 525, Margaret.

MR WALSH: Patricia, is there anything in there about the role of disability support - - -

MS SCOTT: On 525 it actually talks about the disability service organisations assisting individuals during and after the assessment process, about early planning and so on. I haven't checked 7, but I suggest that probably what's happened, John, is the idea is in our heads but not necessarily on paper yet.

MR WALSH: Yes.

MS WARD (BS): I guess the intention is there: understanding the potency of when a family and the person with disability has a very strong vision, has very strong networks, and there is an intentional planning process beyond a service response.

MS SCOTT: Yes.

MS WARD (BS): The service is kept in its place. The service is very insidious, the way it creeps in.

MS SCOTT: That's fine. All right. I think I'm on the same wavelength. Thank you, Margaret. John, any further questions for Marg?

MR WALSH: No. Thanks, Margaret.

MS SCOTT: Thank you for coming along to day. We've got to 12.30, or close to 12.30. We might adjourn for lunch. We will resume at 1.50 with the Spinal Injuries Australia Association. So thank you very much, and we'll see you back at 1.50 if you can make it.

MR WALSH: Thanks, Patricia.

MS SCOTT: Thank you, John.

(Luncheon adjournment)

MS SCOTT: Ladies and gentlemen, good afternoon. My name is Patricia Scott. If you've been here in the morning you know that this is John Walsh who's coming in from Sydney via Skype. In case you didn't hear my earlier comments, we are recording today's proceedings so that other people who are interested in this inquiry can see what people have said and provide comments. If you wish to make some comments at the end of the day, I'll invite people to come forward and make a short statement but it's not a public meeting, so we appreciate that you'll take that into account.

It's my pleasure now to ask Mark Henley to come forward and, Mark, we've assigned 30 minutes for your presentation, with questions from John and I, so you might take into account that we might have a few questions for you.

MR HENLEY (SIA): Thanks, commissioner - and also Col Mackereth, who we indicated - - -

MS SCOTT: Col, that's fine. Sorry, okay.

MR HENLEY (SIA): Thank you.

MS SCOTT: Most welcome.

MR HENLEY (SIA): Thanks very much, commissioner, for the opportunity to talk. Col and I will present on a few issues that we think are important for the Productivity Commission to consider. One of the first things I'd like to say is firstly congratulations on the report. I think there are some excellent things that have been highlighted in the report, particularly I suppose just the acknowledgment that it's actually a dysfunctional system and that it badly lets people down. I think that's a very accurate statement. I think one of the important things we want to communicate is about what are the implications if nothing does happen through this process, and the importance that an NDIS must be linked strongly to a national disability strategy that's been signed off by COAG.

I think we all know what pressures the current health system and the justice system and other systems are under because people with disability are let down so badly. The other thing that is totally unknown to many people in the broader community is about disability and why is it that disability has not got the prominence or the profile that it actually should have for so many years, and the fact that there's an opportunity now to be doing something that's so critically important, and the timing of this. Col was going to talk to his situation of having an injury and we might then flow on with some of the other topics for discussion.

MS SCOTT: All right. Thank you.

MR MACKERETH (SIA): I've had quadriplegia for nearly 33 years now as a result of a diving accident. In that time I have moved heaven and earth to remain independent in every way that I possibly can and I've been successful in being able to do that. In my day there was no SCIR funding, there was no assistance for people with spinal cord injuries, so I had pretty much remained independent for quite a long time. I've worked all my life. I haven't been on the disability pension or the dole in any of that time. I guess now that I'm ageing I'm starting to experience the results of that independence and the consequences that are now starting to compound my own situation. Certainly in the last 12 months I'm really starting to notice, with deteriorating health, and now things like my shoulders have gone.

I've actually got an application in for assistance at the moment. I put it in in about 2005 when I first started to undergo some surgeries and things started going wrong and I could no longer be independent. More recently, about three years ago, I put in an application that I actually hand-delivered to the manager in the North Queensland office and I had a long conversation with him about my chances of getting some assistance, and he said to me, "You know the reality of this, don't you?" and I said, "Well, yes," having worked in the disability sector and actually made applications for other people. Probably the reason why I hadn't applied earlier was that I knew I wasn't ever going to get a package or any assistance.

However, now that things are really starting to compound, my relationship is starting to be affected. My partner is my only carer and she's said things like, "I signed on to be your partner, not your carer," which at the time we started going out she could be, but now that things have changed - see, now that's having a huge impact on my personal life. My health, as I mentioned, because I've not taken the opportunity to try and get care, has deteriorated. I guess, more importantly, my independence and community access and through that - my main area of access is my work. As I said, I've worked all my life. I'm thinking seriously if I don't get some sort of assistance soon then work is no longer going to be an option for me. I guess with that I'll sort of hand back to Mark unless anyone has questions at the end.

MS SCOTT: I could ask questions now, if you don't mind, Col.

MR MACKERETH (SIA): Yes, sure.

MS SCOTT: You mentioned that you work in a disability sector and you're aware of how rationed things are. To what extent would your condition need to deteriorate in order for you to be confident you're going to get a package?

MR MACKERETH (SIA): I think it needs one now.

MS SCOTT: I'm trying to get the difference between needs and what's available.

MR MACKERETH (SIA): I've actually just come this morning from having my eligibility assessment again under the new Growing Stronger system. I don't know that I fully understand.

MS SCOTT: All right.

MR MACKERETH (SIA): Had I been discharged in - - -

MR HENLEY (SIA): What level of crisis would you need to be - - -

MS SCOTT: To be confident you're going to get a package.

MR HENLEY (SIA): Do you think you ever would?

MR MACKERETH (SIA): I don't know. I'd say at risk of being institutionalised or dying, hospitalised. That's pretty much, from what I've seen, the only way to get a package - if you're going to be institutionalised or at risk of dying.

MS SCOTT: Okay.

MR MACKERETH (SIA): That's the way I understand it now and I guess that's probably the option that I'm looking towards the future, that maybe I'm going to be in a nursing home before I'm 55.

MS SCOTT: All right. Thank you. Back to you then, Mark.

MR HENLEY (SIA): Thanks, commissioner. I think that's the importance of the fact: that if people don't have the right supports through what an NDIS could offer, it's the implications on health; someone who's worked all of their life, what it's going to mean for their employment, their relationship, their independence and their dignity. I think this is the only opportunity that we will see where those rightful supports could be put in place.

One of the areas that we'd like to talk about is the importance of training. I think it talks in the report about training and that it may not be necessary for training to be in place. We believe it's incredibly important that there is appropriate and adequate training for all support workers, and particularly I suppose we could talk about people with spinal cord injury. They do need a competent and trained workforce. Quality standards indicate that there must be at least manual handling training, confidentiality, boundaries between client/support worker, also the safety of the client and the support worker. Training is also required for technical issues such as bowel therapy, continence, catheter management, and we could go on about what people's requirements are so they actually can live in dignity in their own home without having to rely on a health system which would totally compromise their lifestyle.

The other question is, if workers aren't required to be trained, then who is actually going to be liable when something goes wrong? I don't think that would be fair to be put back on the person with a disability or a service provider or in fact the person who takes on that work in good faith.

Other areas we'd like to discuss are around quality. There's a lot of talk in the commissioners' report about efficiency, about efficient pricing, costings, and I think one of the most important things is that it's all driven by quality outcomes. Everyone would understand the importance of efficiency but you can still get quality outcomes through efficiency and it's important that quality is not going to be compromised. It's important that the actual person who requires the support has the choice whether they want a service provider or not and who those support workers may be, regardless of whether they're employing them or the service provider.

The other thing around quality is people in regional areas: there's no doubt that in most situations there are going to be higher costs. In regional areas, they don't have the supports around other areas of services that they require. Health services are far more scarce as soon as you get outside of the Brisbane region. Probably Queensland and Western Australia are a bit different from many other states - the fact that the majority of the population live outside of the capital city - and you'll find in even some of the major cities throughout Queensland that you don't have health specialists when people are travelling, as in Queensland there is only one spinal unit and for some people that's two and a half thousand kilometres away from their own home. So the cost of services and the quality of those outcomes is very important; that people get good quality services in their own region.

The other area is around the need for one assessment, one holistic assessment which goes over all systems - whether that's transport, education, personal support, health, but also whole of life - and the only reason for an assessment that should change is where a person has a requirement that their own needs change and they can actually get reassessed at any point in time without fear of losing any services but, also, if they require less services, that they might have that option to put that forward but also to regain services at any particular point in time when they're required.

There are major events that people go through, such as ageing, maybe an elderly carer or work, or problems just with health where people do need reassessment. We think that's vitally important, but more at the discretion of the person with the disability, not at the assessment end for whoever does the assessment.

The last area, if I could, is the importance about retaining the right to compensation for a person who acquires an injury. For a person who acquires an injury, there's in many situations - given that most people acquire a spinal cord injury in the ages between 15 to 30 - a loss of income, there's trauma, pain and suffering, counselling for the individual and family members, housing modifications, medications, transport, recreation, information, assistive technology; many other additional costs incurred from living with a disability.

We would hate to think that a person with a disability loses a right to compensation for any other reason than the fact that there might be a disability insurance scheme in place. That can't replace people's right to some form of compensation, giving consideration to what was there prior to when they had their injury. If you look for another instance - someone had a right to a claim for sexual harassment or whatever it might - people aren't told that they can't claim for sexual harassment if they have a right to it. I know there has been some talk in some areas that people may lose a right to compensation. You would hate to think, because a person had a disability, they would lose any right to compensation in that area.

I shared in a conversation with some people who have received compensation and they can vary between 18 to 22 per cent in many situations, which is only a small proportion of the population who actually acquire a disability around spinal cord injury, but they often say they do not know how they would survive or how they may have kept their family together without that level of compensation to cope with the actual costs and trauma that they've been exposed to. That's it formally from us. Thanks, commissioner.

MS SCOTT: Thank you. Please call me Patricia. John, do you have any questions?

MR WALSH: Mark, I just want to take up the last point you made about compensation. I don't understand what you're getting at there. Could you be a bit more explicit, please?

MR HENLEY (SIA):   John, a national disability insurance scheme I don't think has ever talked about responding to a person's situation where they might have a loss of income. It's more about providing supports that would be available to anybody else with a disability, such as personal supports, equipment. But there are a lot of issues. People have access now to compensation through common law. You might find it through WorkCover or through a motor vehicle accident. In Queensland, we've only got compulsory third party. Other states have no fault. There's a big difference in Queensland, if you are the driver and at fault and if you are the passenger who's not at fault, whether you actually get compensated or not. I think that there's a total inequity. People who have that ability to get compensated are in a very much different situation through that redress than a person who doesn't get any form of compensation.

MR WALSH: What our report is suggesting is that that inequity is removed with respect to future care and support. Anyone who sustains an injury is entitled to compensation for future care and support, but it's not under the common law. It's under a separate scheme, such as in New South Wales. Would you guys advocate that?

MR HENLEY (SIA): Through a separate scheme other than common law?

MR WALSH: So Colin, for example, under what we're proposing, receives full entitlement to future care and support under a national injury insurance scheme, but under the current scheme he would still receive nothing.

MR HENLEY (SIA): Can I just clarify: is that going to be that people would be entitled to loss of income, trauma, et cetera, through that scheme?

MR WALSH: We haven't gone to loss of income. So we haven't affected the common law rights or suggested an extension of those rights with respect to income. Income is beyond our scope. But certainly we're suggesting that entitlement to future care and support shouldn't depend on the ability to prove fault, as it does at the moment. So what we're suggesting is a scheme whereby Col would be fully entitled to future care and support.

MS SCOTT: Effectively he could still sue for loss of income. He could still sue for - - -

MR HENLEY (SIA): Through common law.

MS SCOTT: Through common law and pain and suffering.

MR HENLEY (SIA): That's all right, as long as that's still available to people.

MS SCOTT: Yes.

MR HENLEY (SIA): We would be happy with that.

MS SCOTT: Okay.

MR HENLEY (SIA): And not capped, because there have been conversations about capping what people's entitlements might be. I don't know any other area where things would be capped for people, and why should they be?

MS SCOTT: More questions, John?

MR WALSH: No, I think that's fine, thanks, Patricia.

MS SCOTT: Mark, I want to go to the issue of one holistic assessment. I'd have to say a couple of other people have suggested this to us in some of the submissions we've received and it has some appeal, but I just wanted to check what it actually means. In the report we suggest that, for example, it would be reasonable that if a person was coming for assessment and was going to get an individualised package - they were in the tier 3 group getting an individualised package - it would make sense for the state authorities to allow the NDIA, the NDIS, to issue the parking arrangements, so they'd have their sticker and they wouldn't have to go through that process again.

MR HENLEY (SIA): Yes.

MS SCOTT: But we didn't go the next step and suggest that the NDIA assess for Centrelink purposes, so we didn't suggest it should be the assessment process for disability support pension or Newstart or whatever, and we've got reasons why we thought that was the case.

I just want to check. Would you want it to be more like assessment for everything, or are you comfortable with the assessment into the scheme? It asks Col what he needs. There's an assessment of his needs. If he wishes, he would get a package that he could manage, or if he wishes to nominate a series of organisations or service providers he could nominate them and then they could organise the support that he requires. Do you want it to go further and be a one-stop shop for everything, or are you comfortable that it would just be about care and support?

MR HENLEY (SIA): I think if there is one assessment, and they have the capability to adequately do a holistic assessment, that that would be a much preferred option for people. People have enough to work through when they have a disability, without having to go and seek other avenues of where they find additional support or where do they get assessed adequately. If it can be capably done by one organisation, I think that would be people's strongest preference. Is that answering your question?

MS SCOTT: That's right. I just want to check, though, because it does mean you are starting to blur things. For example, there are 808,000 people on disability support pensions. Now, we didn't think that number of people would ever get individualised packages, but if in fact you see the scheme partly replacing the functions of Centrelink, you can imagine that some people would want to move in the direction of the fund. All right. I think - - -

MR MACKERETH (SIA):   Could I just make a comment on that holistic assessment?

MS SCOTT: Sure.

MR MACKERETH (SIA):   In my own circumstance that would require, for me, more than just the assessment of my personal and household needs. That would include things like community access, other areas, recreational needs, transport needs, accessing employment needs, not just an assessment on what you need to get dressed each day. It needs to be the holistic, in that respect.

MS SCOTT: Yes.

MR MACKERETH (SIA):   I guess that's what it means to me.

MS SCOTT: Yes. No, we had that covered. We had suggested that it would include employment, that it would include consideration of transport needs, and it would include community participation and access. What we hadn't suggested was that it includes Centrelink income support assessment. So we had those other bases covered but not that one. All right. John, any further questions?

MR WALSH: No thanks, guys.

MS SCOTT: I thought you might have wanted to ask a question, John, but let's see. On the training, you may want to have a look at the detailed chapter on that and just see whether you still hold the same concerns. We were trying to distinguish between the level of care and expertise that could be required, and put a strong emphasis on the attitudes of the individual and their behaviour and how much respect they provide to the person. Sure, some people will need to have particular training - catheter management and so on - but for many people it's not that level of sophistication and really it's almost a graduated approach.

In the New South Wales scheme their assessment and discussion between the individual and the assessor leads the person to be able to say, "Well, you definitely need nursing support. You definitely need a trained person." The question is, if some people are happy to take someone without training, would the scheme stop them or not? In some jurisdictions they found it easier to find support workers when they haven't required training. So, for example, if someone needs assistance with shopping or undertaking a task like that, do you really need to insist that they've done a certificate III? Do you have a comment on that?

MR HENLEY (SIA): We share the concern, if you were to have an expectation about people having certificate III or IV, that there are going to be major issues on the workforce-related side. If there was straight domestic assistance, we see that quite different, and maybe some of the implications of a person being supported as a spinal cord injury, there may be some benefits there. However, we are also mindful of the fact that the implications that it has for a person with a spinal cord injury, if you don't have a person who is adequately trained - and it depends on what may arise through their day - there may be some unintended consequences of untrained staff. So it may well depend on the incidence of the type of disability a person may have.

MS SCOTT: Yes, okay.

MR WALSH: Can I just ask Col, as a person with quadriplegia, and you've actually been able to support yourself for 33 years, for someone to support you throughout the day, would they need to have a formal qualification or just someone who - your needs were that you were able to explain to them what you needed?

MR MACKERETH (SIA): They would have to have a basic understanding of some of the things that affect people with quadriplegia; things like autonomic dysreflexia, which you would be aware of, that can be life-threatening for someone with quadriplegia. If I was in a situation where I was at home with the carer and they didn't have the knowledge that they needed to around that particular issue, then yes, I would feel quite uncomfortable. And if I was that unwell that I couldn't communicate what they needed to do, then yes, they certainly would need to have a qualification around that.

I would expect that a carer coming into my home would have a lot of training around confidentiality and boundaries, and understand; like, if I'm inviting somebody into my home to do things of a personal nature that they would at least have a skill level, that they would respect those sorts of issues, yes. There would be cases, yes, certainly, that they would need some level of formal training.

MR WALSH: I'm just curious how you've got on with autonomic dysreflexia for the last 30 years.

MR MACKERETH (SIA): It's not been a serious issue with me until recently, so yes, without getting too personal, it's starting to become an issue for me in the last couple of years, and I actually didn't know what it meant until about five years ago.

MR HENLEY (SIA): Can I add, John, you may well know, but some people know about autonomic dysreflexia within their first months of having a spinal injury. It's very individual.

MR WALSH: Thanks, guys.

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

MR HENLEY (SIA): Thanks, Patricia. Thanks, John.

MS SCOTT: Can I now call to the table Gerry Murphy, please, Matt Dunn and Michael Garbett and Mr Luke Murphy. We might need quite a few chairs. It's almost standing room here, John. We've got quite a crowd, so that's good. Thank you very much for attending, everyone. Good afternoon.

MR G. MURPHY (QLS): Good afternoon, commissioner.

MS SCOTT: Could you please identify yourself for the record, because we're having a transcript made, and we have assigned 30 minutes to your presentation and the opportunity for John and me to ask some questions.

MR G. MURPHY (QLS): Sure.

MS SCOTT: So, when you're comfortable, please start.

MR G. MURPHY (QLS): I'm Gerry Murphy. I'm president of the Accident Compensation Committee of the Queensland Law Society.

MR DUNN (QLS): I'm Matthew Dunn. I'm the principal policy solicitor for the Queensland Law Society.

MR GARBETT (QLS): Michael Garbett. I'm a member of the Accident Compensation Committee of the Queensland Law Society.

MR L. MURPHY (QLS): And Luke Murphy, a member of that committee also.

MS SCOTT: Thank you. Please proceed.

MR G. MURPHY (QLS): Thanks very much, commissioner. I didn't propose to go through in detail all the talking points that we made available to both the commissioners. Happy to answer questions on those. I just thought I should try and address our principal concerns. Before I do that, could I first of all thank you for the opportunity to address the commission this afternoon and, due to the time constraints and the sheer volume of the report, on which I congratulate you, you would appreciate that we're unable to cover all the aspects of the draft report.

MS SCOTT: We appreciate that.

MR G. MURPHY (QLS): We trust that our talking points and our elaboration now initially, or by questions from yourself and Commissioner Walsh, are of some assistance to the commission. We do propose to deliver a more detailed submission in writing to the commission at the end of the month. We would appreciate it if, during the course of our discussion this afternoon, the commission could indicate to us any particular areas it would like the society's input on or any other information it might require specifically from the society.

Could I also before addressing our concerns simply say that (1) if it's possible we would appreciate receiving a transcript of the proceedings today, and (2) if we could be given the opportunity to meet with the commission prior to the release of its final report, and in that respect we're quite prepared to travel to Canberra or whatever is the most suitable for yourself. We mention those two things for the commission's consideration.

In terms of my opening statement, I don't propose to address all the points in the report but just to make the following brief comments, as indicated in the talking points. First, the society supports the commissioners' concept of universal quality care and support for disabled persons in the community, but we say that we do have a number of serious concerns as to the implementation of that concept.

The three major concerns are: firstly, the costing. The commission report goes into some detail in the costing. The society remains unconvinced that the costing models for the scheme will prove accurate and says that any reliance on the New South Wales scheme, or the New Zealand scheme in particular, would indicate otherwise. We say that the New South Wales scheme simply hasn't been going long enough to provide any guidance, but even in the few years that it has been going, there are indications of problems with the funding of that, and so far as the New Zealand scheme is concerned, we say that it simply stumbles from disaster to disaster, and we can quote some statistics on that to support that statement. If the commission thinks that's an overstatement, we're quite happy to support that statement from the last annual report and the financial condition report which was issued recently.

Secondly, we've got concerns about the funding model. We find it difficult, if not impossible, to comment on that until the funding model is determined, and that's one of the reasons why we would like the opportunity to meet with the commission again, if that's at all possible. In the scheme of things, we appreciate that you're working to a pretty hectic deadline.

Thirdly, could we talk on the impact of the commission's proposals on the existing common law rights, and could I say in relation to that that Queensland is in a unique position so far as the common law is concerned. Unlike all other jurisdictions in Australia, there are no restrictions in Queensland on an injured person's right to bring a common law claim. Could I just address the two major areas, which are motor vehicle and workers compensation.

In Queensland there are no thresholds whatsoever so far as the right to bring a common law claim is concerned. That's distinct from other Australian jurisdictions. There are two jurisdictions where the right to bring common law claims in one or other of those areas has been abolished altogether, but there are restrictions - in some cases very severe - on getting over thresholds. Thresholds don't apply in Queensland. In a motor vehicle accident, a person who is injured has an absolute right to bring a common law claim, and in the workers compensation system, provided the person establishes that he satisfies the definition of "worker", he has an absolute right to bring a common law claim.

We say that, given that we have greater elements of common law in those two major systems and in all other claims; that both the Queensland schemes are fully funded, as opposed to the New Zealand scheme which has got enormous unfunded liabilities. Both are fully funded and in both the costs are reasonable, if not minimal. Could I mention that the legal cost in our workers compensation system, if you have a look at the last year's annual report, is 4 per cent. As your report points out, the legal cost of the CTP system - you quoted in your report 15 to 16 per cent, but that includes a legal investigation cost. We say, as we have mentioned in talking points, that the costs, certainly of the workers compensation scheme and even of the CTP scheme, are outweighed by the administrative costs that replace that in the New Zealand scheme.

If I could summarise that, we reiterate our support for the concept of fully-funded quality care for all disabled people, but we say two things: that that should be at a cost that is acceptable to the community, and the New Zealand scheme doesn't give us any confidence that that will be so, and it should not diminish the disabled person's existing rights, and I was interested to hear Mr Henley on behalf of Spinal Injuries Australia reiterate that.

There are one or two other concerns. One of them that we think is worth mentioning is that we couldn't see anywhere that the report deals with overseas visitors and we would strongly oppose this commission adopting the basis of treatment of overseas visitors that the New Zealand scheme does; that is, where they give them medical support and hospital support while they're in New Zealand, but once they return home, they're no longer interested. We don't think it's good enough for any scheme to adopt there, where they have taken away a person's rights to sue at common law. So we think that the treatment of overseas visitors, while minor in the overall scheme of things, is an aspect that should be dealt with by the commission.

Thank you, commissioner, for the opportunity to attend and to address you, and we're quite happy to answer any questions that yourself or Commissioner Walsh may have.

MS SCOTT: Yes, thank you. Thank you very much. We might go with first names, if you're comfortable with that?

MR G. MURPHY (QLS): I'm happy with that, yes. Gerry is my first name.

MS SCOTT: Great. Patricia and John. Gerry, could you help me out here - because you've made some statements about the funding arrangements. We have set out in the draft report, in chapter 12, how we suggest that at this stage it be financed. So I'm just a little lost to understand why you say the funding model has yet to be determined. I just want to get some sense of what - - -

MR G. MURPHY (QLS): As we read your report, you listed five alternatives for funding and then you said that you had yet to determine those. We couldn't see any point in our making submissions on those until we knew which funding model you were going to adopt. Sorry, I did leave one point out, Patricia, in my commentary; that is, that we say if you do it off any model, that model should be a fully-funded scheme.

MS SCOTT: Okay.

MR G. MURPHY (QLS): Sorry, could we just say - and I don't want to keep harping on - that the New Zealand scheme is a prime example of why a fully-funded scheme is needed.

MS SCOTT: On that, we have recommendation 12.2, which is about how we suggest at this stage it should be funded. Would you like to have a look at recommendation 12.2?

MR G. MURPHY (QLS): No, if you give me the summary of that - but, as I say, our reading of the report is, it designated five different courses of funding and hadn't recommended any one of those, and we say that the costs which you've estimated sort of - - -

MS SCOTT: Yes, I understand you're making a question mark about the cost.

MR G. MURPHY (QLS): The cost, okay, good.

MS SCOTT: We also talked about the fact we only had three weeks - - -

MR G. MURPHY (QLS): Yes, I understand that.

MS SCOTT: - - - to work on the data because it came in so late - and we want to do more work - but we do indicate there a preferred option.

MR G. MURPHY (QLS): Sorry, in which one did you - - -

MS SCOTT: 12.2.

MR G. MURPHY (QLS): 12.2? So direct payments to a national disability insurance funding. We'd have no problem with that - - -

MS SCOTT: Yes, okay.

MR G. MURPHY (QLS): - - - provided that the scheme was fully funded as a result.

MS SCOTT: Just on the fully funding, could you just elaborate a bit more about why you want it to be fully funded?

MR G. MURPHY (QLS): Yes, because we think otherwise you'll finish up like the New Zealand scheme.

MS SCOTT: What about fully funding now with the present arrangements? Do you think that should be government policy?

MR G. MURPHY (QLS): We say that the New Zealand scheme is a prime example of that.

MS SCOTT: No, but the current arrangements, do you think they should be fully funded as well.

MR G. MURPHY (QLS): Yes.

MS SCOTT: And the age pension, it should be fully funded?

MR G. MURPHY (QLS): We haven't considered the age pension, Patricia. We've just considered the terms of the commission's report.

MS SCOTT: It's just that there's very few things that are fully funded because of the lifetime cost of things. Age pensions are not fully funded.

MR G. MURPHY (QLS): If we want to venture into other schemes, the government is making a good attempt to fully fund superannuation liabilities. But let's not get into that. That's sort of outside our area of expertise. We're dealing with an insurance scheme basically.

MS SCOTT: But there are insurance schemes that aren't fully funded.

MR G. MURPHY (QLS): Yes, I appreciate that, and they're the ones that create problems. We say we support the concept of people, disabled people, receiving quality care, provided that it's fully funded and that it doesn't - as happened in New Zealand - then withdraw the benefits. They've got enormous outstanding liabilities per capita, per head of population. We don't want to see the Australian scheme degenerate into the situation of the New Zealand scheme.

MS SCOTT: Why do you think New Zealand has retained their scheme for over 40 years?

MR G. MURPHY (QLS): Not quite 40, but close enough, yes.

MS SCOTT: Something like 40.

MR G. MURPHY (QLS): Yes, it is something like 40. They kept changing it. They've been through an extraordinary number of changes. In March last year the New Zealand scheme legislated that they produce a financial condition report, and that financial condition report was produced this year - and I'm reading from the - - -

MS SCOTT: Of course we quote the report in our - yes.

MR G. MURPHY (QLS): Yes, all right. Well, I don't propose to quote it now.

MS SCOTT: No. What I'm seeking to ascertain from you is that, given the deficiencies that you see in the New Zealand arrangement that you've highlighted for us - - -

MR G. MURPHY (QLS): We haven't really highlighted it. We've just mentioned it.

MS SCOTT: No, you mention it here in the testimony.

MR G. MURPHY (QLS): Yes, but just as a general statement.

MS SCOTT: I'm just ascertaining from you - given your view that it's clearly a deficient arrangement and has been for sometime, as you just said - why consecutive governments in New Zealand have retained it. I'm just trying to work out why they haven't returned to the common law - - -

MR G. MURPHY (QLS): They did for a while, you know.

MS SCOTT: Of course, just for a short while, yes.

MR G. MURPHY (QLS): Yes. If you go through the history of it, they've changed the scheme every few years.

MS SCOTT: But it's stayed in place, by and large.

MR G. MURPHY (QLS): Yes. Though mind you, the annual report before last it indicated, in a statement from the minister and then from the chairman, that it was doubtful whether the scheme was any longer sustainable.

MS SCOTT: That's different from retained.

MR G. MURPHY (QLS): Yes, I know, but if it wasn't sustainable, it wouldn't be retained. That's my point.

MS SCOTT: Okay.

MR G. MURPHY (QLS): Yes.

MS SCOTT: You haven't mentioned the Victorian transport accident arrangements. Would you like to comment on them?

MR G. MURPHY (QLS): No, except that we say that you can't get access from the Victorian report, and that in itself, it's integrated with the whole scheme, so we haven't been able to date to comment on that. But we have the same comment as we had with the New South Wales scheme.

MS SCOTT: You'd put that in the same category?

MR G. MURPHY (QLS): Yes, it hasn't been going long enough. With the New Zealand scheme, the holes and the deficiencies in the New Zealand scheme didn't appear for some time, long after four or five years.

MS SCOTT: Right.

MR G. MURPHY (QLS): Can I just quote from that financial condition report?

MS SCOTT: No. Could I just get you to go to another one?

MR G. MURPHY (QLS): Yes.

MS SCOTT: You mention workers compensation a number of times. What recommendation in particular are you referring to in the report about workers compensation, because I'm only aware of one suggestion as it relates to workers compensation. We are suggesting that, apart from one suggestion, there's no changes to workers compensation.

MR G. MURPHY (QLS): That wouldn't concern us at all if they'd allow the Queensland scheme to operate. We are concerned - we think that the Queensland schemes, both in workers comp and motor vehicle, are the best in the country, and they allow full, unrestricted common law rights with some minor restrictions on some of the heads of damage. But we'd support the concept of full quality care if that was integrated into the existing CTP and workers compensation scheme. That wouldn't cause us any trouble at all, Patricia. But we're concerned that it may have an impact if they bring that in and there's talk about a federation. We're not concerned about the imposition of guidelines as long as they leave both our current schemes unaffected.

MS SCOTT: Just for clarity purposes, I'm unaware of any substantive recommendation in the report relating to workers compensation except as it relates to assisting those people who have had a catastrophic injury - and that's just a suggestion, not a recommendation.

MR G. MURPHY (QLS): Okay.

MS SCOTT: Sorry, I've taken the floor for a while, John. You may have a question for these gentlemen.

MR WALSH: No, I'm really just - hi, Gerry, how are you?

MR G. MURPHY (QLS): G'day. Good, John, thanks. Good to see you here.

MR WALSH: Yes, you too. I'm just trying to reconcile your support for a scheme which provides (audio cut-out) the care and support they need with a view that under the common law a lot of people miss out.

MR G. MURPHY (QLS): Yes.

MR WALSH: So how are you going to reconcile those two things?

MR G. MURPHY (QLS): Sure. We say that if a scheme can be produced which supplies to those people who currently miss out, and that can be run alongside the common law scheme, we have no difficulty with that, John. There is talk in the commission report of ultimately, in the year 2020, completely abolishing common law altogether. That didn't finish up, as I understand, as a recommendation of the commission, no, but that concerned us, if that was the ultimate objective to the scheme; that it would completely abolish common law rights altogether.

MR WALSH: What the report recommends is a review in 2020.

MR G. MURPHY (QLS): Yes, but there is talk about the complete abolition of common law rights.

MR WALSH: It talks about reviewing the schemes to see how - in fact, I think in the Canberra hearings recently (audio cut-out) research be gathered on the effectiveness of mutual schemes, so that would be all the review is recommending.

MR G. MURPHY (QLS): Well, that certainly wouldn't trouble us, as long as common law rights aren't interfered with in the meantime and as long as our Queensland - we're very proud of our two Queensland systems, and as long as they aren't interfered with as a result of the introduction of the schemes recommended by the commission.

MR WALSH: In the Victorian scheme, which has been going - - -

MR G. MURPHY (QLS): For seven years perhaps?

MR WALSH: No, about 30 years.

MR G. MURPHY (QLS): The Victorian TAC scheme?

MR WALSH: Yes.

MR G. MURPHY (QLS): Yes, but - - -

MR WALSH: Which has had noticeable access to parent support benefits for - do you have a problem with that?

MR G. MURPHY (QLS): Only if we could see the figures, the costing of that, and if it can be integrated into our existing common law schemes, the CTP and workers comp, that wouldn't concern us at all, John.

MR WALSH: Okay, that's good. Thanks, Gerry.

MS SCOTT: Any further questions, John?

MR WALSH: No, that's good.

MS SCOTT: Gerry, right at the outset you asked two questions. It was about the availability of the transcript today.

MR G. MURPHY (QLS): Yes.

MS SCOTT: Maybe you're used to more speedy arrangements because of your court practices here - - -

MR G. MURPHY (QLS): Sorry, by "today" I didn't mean you give it to us today.

MS SCOTT: Right, of today.

MR G. MURPHY (QLS): Of today.

MS SCOTT: I was going to say - I was looking at our transcript service - - -

MR G. MURPHY (QLS): No, I wouldn't - - -

MS SCOTT: - - - and wondering how they're going to do it.

MR G. MURPHY (QLS): I wouldn't put that on anyone. Sorry if you misinterpreted me.

MS SCOTT: I see. Well, the transcript will be available for today, or of today, and it will be up on our web site.

MR G. MURPHY (QLS): Good, all right.

MS SCOTT: It will be available to all the public from our web site pc.gov.au. In relation to having a meeting, we do receive a large number of requests, which is of course why we try and get out to do these public hearings, so by all means feel free to write to us. But you can imagine that, now I've said that, we'll get letters from lots of other people. Clearly, one of the strengths that we see of our arrangement is that we are actually able to take your evidence on record and have other people comment and we try and do our consultations as much as possible in public.

So while I would welcome your letter, I just think we've got to be cognisant of the fact that there are lots of people who are interested in meeting us on this subject and we received 604 submissions on our work before the draft report was released, so you can imagine that there's lots of pressure, so maybe don't book your plane flights immediately.

MR G. MURPHY (QLS): Well, we didn't intend to. We simply made that as an offer and we certainly didn't intend that to be in private. We're quite happy for that to be in public.

MS SCOTT: Okay.

MR G. MURPHY (QLS):   We've got no concern about publicising our attitudes in our report and our detailed submission we will make available. It will be on your web site, as I understand it.

MS SCOTT: That's right. All right, thank you very much for your time.

MR G. MURPHY (QLS):   Thank you. Thanks, John. Good to see you again.

MR WALSH: You too. Take care.

MS SCOTT: Thank you very much.

MS SCOTT: Just a small change to our program, ladies and gentlemen, and John. We're now going to have Yvonne Campbell from Special Care Clothing. Thank you. Yvonne, thanks for making a change to come forward now. You've provided us with some materials, so thank you very much in advance for that. We've allowed 20 minutes for your presentation and some questions.

MS CAMPBELL (SCCS): It will be much shorter than that.

MS SCOTT: All right, that's fine. We don't mind about that. So please feel free to start your statement. Thank you.

MS CAMPBELL (SCCS): Thank you for the opportunity anyway. My name is Yvonne Campbell. I have the business of Special Care Clothing Solutions. I design, manufacture and retail clothing for people with disabilities. As a provider of disability-specific clothing that incurs GST, we decided in 2006 to make application to the ATO in a private ruling application for GST exemption on this product. We were advised that adaptive clothing did not fit within section 3 of the Medical Aids and Appliances Act. According to the Commissioner of Taxation web site, a medical aid and appliance is GST-free if they meet all of the following three conditions listed in schedule 3 of the GST Act or in schedule 3 of the GST Regulations: specifically designed for people with an illness or disability and not widely used by people without an illness or a disability.

Medical aids and appliances that satisfy all these conditions are GST-free at every point in the supply chain from manufacture to consumer. However, excluding any items or service a person with a disability requires, because it is not specifically designed for people with an illness or disability and widely used by people without an illness or disability means people with disabilities are unreasonably obliged to pay GST on some of the most important and expensive items and services they depend on.

We feel the current process of amending the list is outdated and neglected and, as such, we have taken an interest in the matter being considered by the Productivity Commission in its disability care and support inquiry. We understand that adding exemption to the GST Act increases the complexity of tax laws and can give rise to anomalies. The current process for having disability-specific products included in schedule 3 of the act is a long and lengthy process with no direct entry point for submission, nor anybody to regularly review and amend the schedule. However, there has to be a better way, where people with a disability can access equipment and repairs, home renovations and items required for their wellbeing GST free.

A few examples where GST is paid, although it relates to an item for a person with a disability, are spare parts for a medical aid. A further inequity occurs where people with a disability require replacement parts for a mobility aid or medical appliance, despite the original medical aid having been purchased GST-free. In regard to repairs to GST-free medical aids and appliances, the Commissioner of Taxation advises suppliers:

> The following parts or labour you supply to repair GST-free medical aids or appliances are taxable when the parts are not specifically designed as spare parts for GST-free medical aid or appliances and which are not merely incidental to the supply of GST-free specifically-designed spare parts:
>
> Consumables such as oil or glue used in the repair of services that are not merely incidental to the supply of GST-free specifically-designed spare parts; specifically-designed spare parts for the GST-free medical aid or appliances that are not merely incidental to the supply of labour component or the repair thereof -

and so it goes on. Modifications to accommodation: the Commissioner of Taxation schedule 3 limits GST-exempt medical aids in accommodation to items such as bidets, bidet toilet attachments and special door fittings relating to the disability of a particular person. However, examples of goods and services which are not GST-exempt include acquiring and installing cement or steel permanent ramps to replace external steps, modification to widen front and internal doors, alterations to kitchens to raise or lower benches, alterations to bathrooms including installing non-slip floors as well as removing hobs, adding and fitting easy-operating tapware et cetera. The list goes on.

Under the scope of the review 1 in your draft report, 11 February, the commission is to examine a range of options and approaches including international examples for the provision of long-term care and support for people with severe or profound disability. Our recommendation is that schedule 3 of the GST Act be reviewed and amended to better meet the needs and relieve the financial burden currently experienced by people with a disability, or to be based on a similar tax exemption model used by Revenue and Customs in the United Kingdom. The HMRC uses a model that covers both disability-specific products and services and covers the person with the disability for those products or services that do not meet the criteria of the VAT exemption, which is like our GST, as a disability-specific product.

For purchasing products or services that are not tax-exempt from HMRC, they have implemented the following conditions for tax-free purchases which are eligible to be purchased at a zero rate of tax: when the customer is eligible to purchase goods at a zero rate; the goods are for the personal or domestic use of the customer; and the goods and services are eligible to be provided at zero rate. The customer in the UK completes a personal declaration form at the point of purchase to receive the goods tax-free.

As highlighted in your participants' comment section of the report, by not meeting properly the costs of disabilities, you're putting more stress on those carers and you're probably causing more suicide, divorce, separation and abandonment to people with a disability or their carers in the extra burden or cost of paying GST.

We highly support the commission in proposing a national disability insurance scheme, a national injury insurance scheme, overseen by the new organisation the National Disability Insurance Agency, and recommend that people registered under these schemes who are acknowledged to be people with a disability could complete an eligibility declaration at the time of purchase to enable the supply of goods and services to be GST-free; therefore the terms to read, "Goods are eligible to be purchased at zero rate of tax when the customer is eligible to purchase medical aids and appliances at zero rate when NDIA-registered; the goods are for the personal or domestic use of the customer; and the goods and services are eligible to be provided at zero rate." Thank you.

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

MR WALSH: No. It's not really my area of expertise, Patricia.

MS SCOTT: All right. Well, thank you very much for making the submission. I just have one or two clarifying questions. Is my understanding right that a wheelchair might be GST-free, but then when you need - let's say it's a powered wheelchair. When you need to replace the battery, the battery will be subject to GST?

MS CAMPBELL (SCCS): That's correct.

MS SCOTT: And for a manual wheelchair, the manual wheelchair might be GST-free but in fact when you get to replace the wheels you might be subject to GST on those?

MS CAMPBELL (SCCS): Certain parts, yes, I believe so.

MS SCOTT: And you might not accept the rationale, but I just want to check my understanding of the rationale. It goes like this: that because batteries can go in cars or, I don't know, on a mobility device or in a go-kart, they have to be subject to GST. That's the logic.

MS CAMPBELL (SCCS): That's correct.

MS SCOTT: And your logic is that if someone is already, for example, in the scheme as we've suggested, they could simply sign a declaration and say, "That battery was for my motorised wheelchair."

MS CAMPBELL (SCCS): And, of course, the supplier would also have to acknowledge that it was to be for that specific purpose.

MS SCOTT: Okay. Now, you've been making representations to the Tax Office for some time on this.

MS CAMPBELL (SCCS): 2006, and other colleagues have been doing the same thing.

MS SCOTT: And in the case of the trousers, the adaptive clothing that you produce and design, do you sell them to people other than people with disabilities?

MS CAMPBELL (SCCS): No, because a lot of the designs, you wouldn't be walking around in them. They are specific for people with a disability. And it apparently is because there is no act for adaptive clothing. Under that section, schedule 3, of the GST Act it's not considered.

MS SCOTT: Because it's not seen as a medical aid per se?

MS CAMPBELL (SCCS): Absolutely.

MS SCOTT: And it's not seen as an appliance.

MS CAMPBELL (SCCS): No.

MS SCOTT: All right. So in terms of the three conditions, I think you stipulated at the start that (1) it would have to be in the schedule, so clearly the trouble is it's not in the schedule.

MS CAMPBELL (SCCS): Exactly.

MS SCOTT: And the second one, like a battery issue, it's got to be very specific to someone with a disability, not more generally used.

MS CAMPBELL (SCCS): That's right.

MS SCOTT: Your product clearly - you know, there's not fashion models wearing your open-back trousers.

MS CAMPBELL (SCCS): No, not at all.

MS SCOTT: Right. And the third condition was? Just remind me.

MS CAMPBELL (SCCS): The third condition was "not widely used by people without a disability; specifically designed for people with an illness or disability", and that, as far as I was concerned, fitted within that, but they said "no".

MS SCOTT: Okay. Has the Tax Office acknowledged the second point and the third point?

MS CAMPBELL (SCCS): Yes. They actually responded back with exactly that, saying, "It doesn't fit because this is what it's got to fit within." Andrew Wilkie, member of parliament in Tasmania, has also made application for it to be, and he said because there is no act, a bill has to be passed into parliament.

MS SCOTT: All right. And what you're suggesting is, at the same time as the government could be preparing legislation for the scheme that the commission is suggesting at this stage, it could also be addressing this.

MS CAMPBELL (SCCS): Taking the GST under the same umbrella. When you look at the parts, there's one company that sells 3000 parts and 1050 of them are not GST-exempt and the others are, and yet they're all for maintenance for people with mobility aids.

MS SCOTT: Very interesting. I'm trying to remember 604 submissions, so I may not be doing you justice, but have you provided to us the advice you received from the Tax Office?

MS CAMPBELL (SCCS): I did.

MS SCOTT: All right, so we've got that on record. Okay, I'll look that up. Thank you very much.

MS CAMPBELL (SCCS): That's all right.

MS SCOTT: I've got one more question though. If a scheme such as we have suggested was implemented and people received assistance - let's say someone needed to have trousers such as you produce and they received an individualised funding package. Let's say that they had a condition and they received an individualised funding package of, say, $5000 or $10,000, depending on their circumstances, and they could then purchase your trousers, effectively with that money, would that remove for you the necessity for the GST exemption?

MS CAMPBELL (SCCS): I'm quite happy to remove the GST completely as long as they don't have to pay that GST, and if it came in under a package, yes.

MS SCOTT: Okay. Let's make it easier. Let's make it the wheelchair, because we have heard a couple of people have been told by their specialist that they need a wheelchair, and they might receive from their jurisdiction part of the cost of the wheelchair. I think we heard from someone this morning that a motorised wheelchair can cost up to 25, 30 thousand dollars. If the government funded the total cost of the wheelchair, including the GST, they wouldn't need it to be GST-exempt, would they?

MS CAMPBELL (SCCS): No. That's true.

MS SCOTT: So the same could apply with your adaptive clothing. If for example the government didn't want to pass a special bill to make open-back trousers GST-exempt, provided the people got sufficient funding to be able to buy open-back trousers, that's the other way that they could address this issue. Yes?

MS CAMPBELL (SCCS): Yes, absolutely. But I do find that it's people at home, as well as in care homes, et cetera, that actually need adaption to clothing.

MS SCOTT: Okay. If somebody is in a nursing home, they would probably be able to buy it and get the GST effectively refunded. No?

MS CAMPBELL (SCCS): A lot of the time it's families buying - - -

MS SCOTT: Yes, I understand that, but if they're actually in a nursing home, I think that would be the case. Well, look, Yvonne, thank you for drawing this to our attention.

MR WALSH: I am interested, Patricia and Yvonne, in the demand for this service. Do you have many people who know about your service and use it?

MS CAMPBELL (SCCS): Yes, most definitely. In nursing homes. I've also had calls from America, where they actually can't find what they're looking for in America and I've redesigned clothing for them.

MS SCOTT: Anything else, John?

MR WALSH: No, thanks, Patricia.

MS SCOTT: I'll try and be diligent and look up your tax material.

MS CAMPBELL (SCCS): I'll make sure I've sent it.

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

MS CAMPBELL (SCCS): Thank you. Thanks for the opportunity

MS SCOTT: So, everyone, we're going to have a break for 20 minutes and we'll see you back here at 3.20. Thanks, John.

MS SCOTT: Good afternoon again. Thank you for attending this afternoon. If you've just joined us, my name is Patricia Scott, and John Walsh will shortly appear on the screen, but he's definitely here with us in terms of telephone technology. What we're going to do is invite Sam and Anne Mauchline to come forward to give their testimony and we'll probably then follow on with Endeavour Foundation. That means after Endeavour Foundation has presented, if there is anyone who wishes to make a short public statement and wishes to be on the transcript - you might have heard something today that you want to comment on - I will invite you to come forward. But it would be great if it wasn't all of you and you didn't all want to speak for half an hour because we really do need to finish on time. So if you have a few things you want to say, we would be happy to take those comments.

So thank you very much for coming along today and would you like to make a statement? We have allowed 20 minutes of time for you to present and to answer our questions. Over to you.

MS MAUCHLINE: I'm Anne Mauchline and I am the mother of a very severely disabled young boy. My thing is the time frame has gone right out to 2018 and that seems an awful long time for us. We haven't got that on our side, as you can see our age, and we think it should be shortened to where we can see our son is going to be right at the end of it. That's our estimation of it.

MS SCOTT: How old is your son now?

MS MAUCHLINE: 40, and he is in a community home.

MS SCOTT: All right.

MS MAUCHLINE: The funding is New South Wales funding which - you can't come into Queensland where we live, and it's what they call block funding.

MS SCOTT: Block funding, yes.

MS MAUCHLINE: Which I call trade funding, slave trade funding. Also, there's another question: what happens if this isn't going to be implemented, NDIS, because it's not a surety, is it, at the moment?

MS SCOTT: The commission has been asked to do this work, but at the end of the day, you're right: it's entirely up to governments to decide these things. It's not really within either John's power or my power, but we try to do - - -

MS MAUCHLINE: Yes, we understand that, because a lot of disabled people think this is going to be "the" thing for them. They don't realise it might not happen, but we do. And these assessments, they must be mandatory. Our son was assessed. He was A1, which is the highest, and yet he was put in independent model. Now, you do not put a very disabled child - he is a child to me - in an independent model, which caused awful problems; being left by himself with nobody, and this is someone who can't do anything for himself. So, yes, we've been through hell.

Also, there seems to be a high focus on the young. They seem to be getting a lot more preference. They seem to be put first among everybody else. We have done the hard yards because we had our son at home with us until he was 23 or 24 so, yes, I know what I'm talking about and, yes, I know what the young are going through, because we went through it ourselves. Nursing homes: at the moment, those who come out of nursing homes get more funding than those who kept them at home like us. That seems to be wrong to us; it seems to be getting back to front. And also intimidation with care providers is very rife.

MS SCOTT: Anne, just to clarify: your concern is there, if you complain about services, that that will adversely affect in future what's made available to you or your son?

MS MAUCHLINE: Yes.

MS SCOTT: All right. Okay.

MS MAUCHLINE: And also they should get the lease on the houses. They haven't got leases at the moment. They call them "community homes". They used to have leases but they've changed it and this sort of puts them in a very vulnerable situation, so there must be a permanent lease for the person who is in the house.

MS SCOTT: Yes, I understand.

MS MAUCHLINE: That was all I wanted to say.

MS SCOTT: Thank you. Sam, do you wish to - - -

MR MAUCHLINE: Yes. My name is Sam Mauchline. I'm the father of Lucio Paul and I've been through the report quite extensively and I find a lot of things that disturb me greatly in this report. But to lead up to the report, I have a statement to make. Prior to the Howard-Rudd election, a group from Canberra - probably FaHCSIA - went around Australia and held seminars, asking what people with disability are put through and what's wrong with the system and how can it be rectified. We were told at that point in time that the report that came out of those meetings was unilaterally agreed to be accepted and acted upon by the government that won the upcoming election.

Unfortunately, when Rudd took power, he ignored that. Again, he set up another special committee, sent them around the country. We attended the one in Brisbane: all the same stories came out again; all the same recommendations came out again. Eventually that led to a document called Shut Out, which we all knew about five or six years ago. So had Mr Rudd - seems to be the thing with politicians; can't stick to their word - implemented that report and handed it to the commission, the commission would have finished their studies well and truly by now and we would have possibly had a system up and running this year or no later than next year; two years of saving, two years of funding down the drain that could have been used for those with disabilities; two years of stress taken out of our life. This was sheer politicking and I'm not impressed with it. I don't trust any governments of any persuasion. So that's the end of that little bit.

At the beginning of taking people with disabilities out of institutions and going into what they call community homes, et cetera, individualised funding did exist at that point in time and it was federally controlled; exactly what's being said in this report existed at that point in time. The only exception was that the funding did not cover equipment. Basically, that was the only difference. It was purely care money. The equipment came from other departments within governments. So what we would like to say is, the 12-month trial they're proposing, absolutely no need for it. We've already been there. We've done that.

If you go back and ask people like us, you'll find out it worked quite well. The person with a disability, the families and carers had total control over the house they were in, including interviewing and hiring of the staff and the running of the house. It was all there, but through the years, bit by bit, it's been taken away from us and given to the care provider. So in our opinion there's no requirement for a trial period of 12 months. We believe - I'm just being a bit sarcastic - it's another delaying tactic by the government to drag it out.

Now we get to the report saying, when it starts off, they will be looking at people in nursing homes, et cetera, and there will be a priority system set up. That concerns us greatly. The reason behind that is Paul is already in a community home, he already has funding - it's underfunded as well - and this could lead to him being classified as a very low priority person and therefore he could possibly wait until 2018 before anything occurs. These waiting times, as Anne has said - and I will support it 100 per cent - are outrageous and totally and absolutely unacceptable to us.

So what we would like, very much so, is interim measures to be brought into play. These interim measures would kick off - before I go on about that. I understand this is a complicated system, don't get me wrong, and we do like NDIS as a concept and it's a complicated system to set up. But let me draw a parallel here.

On Questions and Answers on the ABC, Bill Shorten was asked a question about the carbon tax. His reply was, in part, "Carbon tax is just a name at the moment. There's nothing in it" - nothing in it. But by the middle of next year - and it's another complicated tax - they will have all the information packaged up, put in there and released July of next year. Why can't this be done by NDIS?

MS MAUCHLINE: Why the long delay?

MR MAUCHLINE: Therefore, that brings me back to the interim measures. If they're going to persist, it's going to go this long. We would like to see at the beginning of next year interim measures put into place. Most of these would not cost any great amount of funding and they are as follows: individualised funding. They already get that at the moment. It's just hidden at the moment.

MS SCOTT: Hidden as block funding?

MR MAUCHLINE: Yes.

MS MAUCHLINE: Block funding.

MR MAUCHLINE: Block funding should be scrapped immediately. Individualised funding does exist in some other states at the moment, but it doesn't exist in New South Wales where our son lives. So it's basically a paperwork exercise. Also, the ability of someone with a disability to reside anywhere in Australia where they so choose to do. They can't do at the moment.

MS MAUCHLINE: Can't do at the moment. Too many hoops to go through.

MR MAUCHLINE: Tried that; got there; can't get there.

MS MAUCHLINE: Too many hoops.

MR MAUCHLINE: The power to be taken from the care providers and given back to those with disabilities, the families and the carers. At the moment under block funding in New South Wales - the person from the legal group mentioned New South Wales as a possibly good example of disability services. It's an absolute mess; absolute rotten mess.

MS MAUCHLINE: Yes.

MR MAUCHLINE: Because it's block funding, the most insidious type of funding that was ever dreamed up. Why? It gives the care provider total control of that money and total control of our son's life and many, many others like him.

MS MAUCHLINE: And they can do what they want with it.

MR MAUCHLINE: And we've been told, face to face with a care provider, once the cheque appears in their account they can do whatever they want with that money. Unacceptable. So that has to happen. That's basically it: the discontinuance of block funding; the power taken away from the care providers, et cetera; put a stop to intimidation that's currently rife within the sector. Examples of this are, when we question something that the care provider does, the first thing they throw at us is an OH and S issue. I then throw back at them, "But you're ignoring the Disability Services Act." I even quote the section in the act that they're ignoring. They come back to me again and say, "Oh, OH and S overruled Disability Services Act totally." Incorrect; absolutely incorrect. We know that's incorrect because we've researched it.

MS MAUCHLINE: They get around it.

MR MAUCHLINE: Believe you me, we've searched every damn thing under the sun. Are we angry? We are absolutely fuming. This already mentions the fact of the priority scheme, et cetera. Like the people from the legal place, we are concerned about the funding situation. The enormity of the cost of this system is beyond us to even conceive the amount of money they're talking about, but it does bring up one thing we think is quite clear: it will have to be a tax on the general public to support it. They're saying that there's a carbon tax coming in next July. There's no way in the wide world the common person out there in the street, struggling already under high water rates and high every other rates, is going to be very happy with another tax. I don't think they will accept it.

MS MAUCHLINE: No, I don't either.

MR MAUCHLINE: So we have grave doubts. As Anne said, there's a possibility the scheme may not even get up and running. Well, in fact, two senior members of this present government have already stated that. There was a program on television on the ABC and it was about parents who were taking their adult children or their young children back to the UK to a better service. At the end of that program, Bill Shorten got up and mentioned the NDIS, et cetera, and then he quietly said, "But there's a possibility the system may never occur. This system may never occur."

More recently, up here in Brisbane - I think it was a federal government out-of-Canberra meeting; I can't be sure of that, but it was something to do with the federal government - someone had some time with Wayne Swan, I believe after the meeting, and they asked Wayne Swan directly, "Is NDIS going to happen or is it not?" His answer was, "Well, the first thing is, nothing will happen till the middle of the year." Wrong (indistinct) happen till the middle of the year. Then he says - and listen to this very carefully - "Once we have the report and gone through this report, we will then decide" - "we" will then - "we will then decide what sort of system will be put in place, and then it will only occur if the funding is available." That's two senior members of this present government casting doubt on this system, and that's about where we are at the moment. Thank you for that. Sorry if I get a bit fired - - -

MS MAUCHLINE: Carried away.

MR MAUCHLINE: Carried away, but it's - - -

MS SCOTT: John? Thank you.

MR MAUCHLINE: Just one quick thing.

MS SCOTT: Sorry.

MR MAUCHLINE: Sorry about that. That's what we've been put through by the New South Wales government and DADHC.

MS MAUCHLINE: DADHC and the care provider.

MR MAUCHLINE: And the care provider.

MS SCOTT: Thank you. Thank you for that.

MR WALSH: Thanks very much, Sam and Anne. It's absolutely good to hear your feelings. I think, as the draft report found, the existing system is not working, so people have every right to be asking these questions. I have a couple of questions for you. You mentioned that the system used to give individual funding, and it worked well, and then service providers managed to get their hands on it - or words to that effect. Do you have any references for that system that you're talking about?

MR MAUCHLINE: What happened was it became model funding - so-called model funding. That's when they took the house - - -

MS MAUCHLINE: Individual funding.

MR MAUCHLINE: - - - and they took maybe three or four residents, and all of those residents would have individual funding through an assessment process. Then they put all that money into what they nicknamed the one bucket.

MS MAUCHLINE: The bucket.

MR MAUCHLINE: Then the care was provided out of that. Then in 2009, was it - the middle of 2009?

MS MAUCHLINE: No, earlier than that we got - - -

MR MAUCHLINE: Block funding.

MS MAUCHLINE: - - - block funding and that is the worst funding you can get.

MR MAUCHLINE: It's the most insidious type of funding they ever thought about - - -

MS MAUCHLINE: And that's what our son is on at the moment.

MR MAUCHLINE: - - - because it gives the care provider absolute total control of what they want to do with that money.

MS MAUCHLINE: Total control of everything, and the house.

MR WALSH: Could you describe for us what it is about the current arrangements that your son is under that - - -

MS MAUCHLINE: Funding.

MR MAUCHLINE: Yes.

MR WALSH: Funding? So does that mean he doesn't get the support he needs?

MS MAUCHLINE: No. It's just block funding. Basically it is individual funding. We know the package he gets, but everybody in the house - it all goes in one bucket and then it goes to the care provider as one and that care provider can do what they want, how they want, and that's when it all goes wrong.

MR MAUCHLINE: There's no documentation regarding how much care a person gets under this type of funding. For example, Paul had what they call a snap carried out by DADHC to identify his needs, and that goes into hours per day, one-to-one care, et cetera.

MS MAUCHLINE: Categorised as A1.

MR MAUCHLINE: When that wasn't happening, and we went back to DADHC and said, "Why is this being ignored?" they say to us, "It's only a guideline. It is only a guideline."

MS MAUCHLINE: And that's when they put him in an independent model.

MR MAUCHLINE: And that's where - -

MS MAUCHLINE: And that was someone A1.

MR MAUCHLINE: That's where everything falls apart.

MS MAUCHLINE: And that's when we decided we had to find out more about Disability Services, and that's when we started getting everything about it.

MR MAUCHLINE: DADHC New South Wales even ignored their own web site. They say it's very transparent when they deal with parents. They say they want parents, carers, et cetera, and the person with a disability involved.

MS MAUCHLINE: No.

MR MAUCHLINE: They ignore you.

MS MAUCHLINE: We were never told he was put in an independent model, because we told them twice, "No, they would not meet his needs."

MS SCOTT: Just to illustrate the gap between what he was assessed and then what he got, does it say there, Sam, how many hours of one-on-one care he was to get?

MR MAUCHLINE: Yes.

MS MAUCHLINE: Yes, everything.

MR MAUCHLINE: They came up with 8.5 hours one-to-one, plus what they've termed an "active night".

MS MAUCHLINE: Which means the person doesn't sleep.

MR MAUCHLINE: It means the person doesn't sleep.

MS SCOTT: Yes.

MR MAUCHLINE: So we went back to them and said, "Look, Paul can get by with a sleepover situation."

MS MAUCHLINE: Just occasionally somebody will need to see to him.

MS SCOTT: Yes.

MR MAUCHLINE: And that means - - -

MS MAUCHLINE: One night a week and a few more hours to the

MR MAUCHLINE: - - - it doesn't cost as much. We therefore said, "That being the case, we're willing to forego the active night - - -"

MS MAUCHLINE: Sleepover.

MR MAUCHLINE: "- - - go to sleepover, and increase the 8.5 hours to about 15 hours per day," and they say, "No" because there is no such thing as any allocated one-to-one. Nothing.

MS SCOTT: I've got it. When they went to the independent living model, he didn't get the 8.5 hours?

MR MAUCHLINE: He got nothing.

MS SCOTT: He got no hours?

MR MAUCHLINE: No.

MS SCOTT: He was just basically - - -

MS MAUCHLINE: He was left. As I keep pointing out, he's a very severe - - -

MS SCOTT: Yes.

MS MAUCHLINE: Not mentally; physically.

MR MAUCHLINE: Physically.

MS SCOTT: Right.

MS MAUCHLINE: And yet he was left night after night - this is evening - by himself.

MS SCOTT: Yes, okay.

MS MAUCHLINE: Even if he wanted to change the channel on the tele - - -

MS SCOTT: He couldn't do it?

MS MAUCHLINE: - - - go to the toilet.

MS SCOTT: Couldn't do it?

MR MAUCHLINE: No. When we investigated this, and had meeting after meeting, suddenly out of the blue the house he was in - they said, "Oh" - he was eventually moved out of there, which we didn't want, and put in another one.

MS MAUCHLINE: Which he didn't want.

MR MAUCHLINE: He didn't want.

MS MAUCHLINE: He didn't want either.

MR MAUCHLINE: They said the reason for moving him was that the funding was insufficient to support him in that environment. So therefore they must have taken him in under a package that was - - -

MS MAUCHLINE: That they hadn't told to us about.

MR MAUCHLINE: - - - incapable of providing his support.

MS SCOTT: Yes, okay. I think we've got your - - -

MS MAUCHLINE: I think you've got it.

MR MAUCHLINE: What we're saying, the important thing, by the beginning of next year, for goodness sake, at least get individualised funding into place as an interim measure.

MS MAUCHLINE: Yes.

MR MAUCHLINE: That will at least give people like Paul - - -

MS MAUCHLINE: A better life.

MR MAUCHLINE: - - - a chance of life - - -

MS MAUCHLINE: Of their life.

MR MAUCHLINE: - - - which he hasn't got at the moment.

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

MR MAUCHLINE: Thank you.

MS SCOTT: Thank you.

MR MAUCHLINE: I appreciate your time.

MS SCOTT: Thanks, Anne. Thank you.

MS SCOTT: All right. We now ask Endeavour Foundation to come forward, please.

MR WALSH: I'm just going to duck out for three minutes. I'll be straight back.

MS SCOTT: Sure.

DISCUSSION RE PROCEDURE

MS SCOTT: Thank you for coming along today. Could you identify yourself for the transcript, please, and then make your short statement.

MR BARBAGALLO (EF): Yes. My name is David Barbagallo. I'm the CEO of Endeavour Foundation.

MR ROWE (EF): My name is Geoff Rowe. I'm the general manager policy, research planning and strategy, with the Endeavour Foundation.

MS SCOTT: Thank you. Please go ahead.

MR BARBAGALLO (EF): Firstly, as you are obviously acutely aware, we've had an opportunity to talk with you previously and at that time we said - and I wanted to put this on the public record - that despite the issues that have come up, and it's a system that's obviously broke - and I think the work that the Productivity Commission has done is landmark work and that it's finally stated in clear language and synthesised the various representations that you've had, "This system is broken," and I think it's a fabulous report in that sense. Does that mean that it can't be improved? Of course not. I think, by and large, it was a great effort. As I've said to you previously, as someone who for obvious past sins in a previous life has read several Productivity Commission reports, it's one of the better ones by a long shot and I mean better in the sense of clarity and really addressing the issue.

Endeavour Foundation has already made a submission. We've had the opportunity to influence other submissions of organisations that we're members of, like NDIS and so on. I guess the emphasis that I wanted to make in my statement today will be in our further submissions. I think it's very important, for example, that the final report pays some attention to the economic consequences of doing nothing.

We're of the view, because of the inequities and the inefficiencies and the nature of nine separate systems in the country at the moment, that the overall national economic impact of doing nothing would be roughly equivalent to what you're proposing. In a sense, you can spend an additional $6 billion and get $12 billion and, we suspect, an even better outcome, or you can do nothing. It will still cost you

$12 billion, and you'll get only a marginal improvement, if at all, and you'll be further impacting on the lives of people that we've just heard from.

The other thing - and I've spoken about this before - is I think it would be important to actually articulate and model some of the knock-on benefits to the other sectors. There's reference to this in the current report, but it's our view from our considerable experience that by taking some of the load off our current overworked hospital system, by taking some of the load out of the criminal justice system and the great injustices that are caused there, by impacts on the para health systems, aged services and other services that governments provide, that there are significant economic benefits to be gained from the introduction of a national disability insurance scheme and quantifying those benefits will give increased courage to our political leaders, I would suggest.

The report also, by inference, talks about the potential for employment outcomes for people with disability. Endeavour Foundation is the largest provider of employment for people with disability in the country. I think it's fair to say that we are of the view that there is enormous potential that's not being realised for people with disability, not just in the type of Australian disability enterprises. We have a philosophical commitment to people with disability moving into open employment, and employment in the community generally, and not necessarily in Australian disability enterprises. There are quite complex issues about choice, and families wanting security of their family members, and these are often vexed questions, but at the moment there's largely no choice, so we very much advocate for increased emphasis on open employment for people with disability.

The other thing that we'd like to see is some modelling done on the knock-on benefits to the economy, because currently what traditionally happens when a family member has a disability is that the mother or the wife is taken out of the employment career path; family members pursue suboptimal career outcomes because of the additional responsibilities in the home, because they're not getting the timely early intervention that would allow them to pursue perhaps more traditional career paths were those support services in place. We certainly know from evidence; I believe Francis Vicary appeared here today for Queensland Disability Network.

MS SCOTT: Yes.

MR BARBAGALLO (EF):   Living proof of the value of support: someone who is a notable contributor, not just to the disability sector but to the entire working community. If we were to once again model these and articulate these, I think it provides real economic evidence as well as the obvious benefit we all get from being in employment: a sense of self-worth, a sense of contribution, a sense of community and so on. So there is significant scope, I believe, for the commission to address those issues in its final report.

One of the other things - and I hope that previous speakers don't mind me referring to this. By the way, there is individualised funding in Queensland but insufficient - I'm the CEO of one of the largest service providers in the country. We have no problem with individualised funding. In fact, I think the previous speaker claimed he was fuming. I thought he was very calm, given the circumstances, actually. We see that frustration all the time. The number of people in this sector who suffer those sorts of indignities and humiliations of a system is just inappropriate, and that will be one of the great outcomes from an NDIS, I would suggest. So we have no problem with that.

I have to say, you need to be careful in going from one system to another without increasing the capacity of the community, of families, and of organisations like Endeavour, to work in that environment, otherwise you run the danger of ending up with a Coles-Woolworths type thing. You think block funding is bad. I throw up Coles-Woolworths as an outcome for those farmers who want to get a decent price for their things.

So that just goes to this issue of how do we build capacity and ability within the community, within organisations like ours? I think it would behove the commission to look at the issue of training, and ongoing training, for the National Disability Insurance Agency. This is not something where you can just train up people and send them off on a course. It's really an area where there's still insufficient research done on people with disability, particularly intellectual disability, and that needs to be fed back into the system. Organisational and community capacity I think are issues that really need to be addressed in the short, medium and ongoing terms.

It's interesting that I've posed this question previously about the potential impact of something like the NDIS, and often people presume that because I'm from a large service provider I'm worried about radical change, and they cite all of the overseas experiences where there's only incremental change when these things happen. I put to the commission that actually what we want is radical change, because the system is not just a bit broken, it's badly broken. So the challenge for me as the CEO of a very large organisation is for us to be more nimble, but do the rights of an organisation sit above the rights of people as individuals? I'd suggest not.

In that sense I think we are very conscious of the concerns of family members and carers and I think we have to design a system that tends more to radical change than incremental and evolutionary change, because organisations like Endeavour Foundation - and I hope people understand that I have some of the best employees you'd ever get in an organisation. I'm not from this sector. When I came here, it was a real joy to come into a sector where everyone was there for the right reasons. That was a good thing, and they do strive hard, but does that mean that the organisational outcomes are optimal? Not necessarily.

So it's a challenge, in starting up a new system like this, that you don't just ever so slightly change the way you did things before, and I don't envy your task of dimensioning that process. I think the trial process is a good one: I think perhaps a number of trials to help both dimension and understand where the actual pressures and our understandings of the new system might operate in a more efficient way are fundamentally important.

I also ask that the commission looks to commission further research on the datasets that are needed to underpin a lot of this information going forward to 2014 and, for that matter, to 2018, because it's really only with empirical datasets and evidence based research that we will be able to come out with the best possible system.

It seems to me, as a citizen of this wonderful country, that the challenge of building the best disability system in the world is not beyond us. We do so many things well in this country, and we should rise to this challenge. Insofar as the draft report of the Productivity Commission goes, I think we have made a great start. As I said, we'll be addressing those issues at length in our resubmission, but I'm conscious of time and the fact that there are individuals here who would like an opportunity to address the commission. Geoff, is there anything further that I may have said?

MR ROWE (EF):   I just wanted to add a comment, and I guess it's something that's come out of the focus groups that have been conducted as part of the sector-wide campaign in support of an NDIS. One of the things that concerned us is that while in these forums you're speaking to the converted - we know the system is broken, we know there's a huge level of unmet need - the broader or the average citizen in Australia doesn't see that there's a problem and they actually have trouble reconciling the fact that in the Lucky Country we have people who are in such dire situations.

One of my concerns is that when this report hits parliament, while you've got a lot of evidence that you're presenting, that broader view out there that's not an informed view will somehow take precedence. So I think it's really important that the report highlights the fact that there is a dichotomy within Australia about the view of the current system, but for those who have done the research and done the work, clearly, as per your report, the system is broken and that there is significant benefit in addressing that.

MR BARBAGALLO (EF):   We'll take easy questions.

MS SCOTT: Thank you. I thought I should clarify something. David, you suggested that we commission further research now and so on. We have until 31 July full stop. We won't be doing further work after that date. Our task will be finished then and unless we get further instructions from the government to do further work we won't be doing further work in this area as part of our normal inquiry process.

In terms of, Geoff, your point about the need to stress the dichotomy, occasionally people have said to me, "Well, the commission is not advertising or advocating," and I need to, just for the public record - I know you didn't say that. But we used to do reports on razor blades and automotive vehicles, and more recently we've done things on maternity leave and gambling, but also wheat delivery systems and so on. I mean, our work is to do investigations, not to do advocacy. So I understand the point you're trying to make - that we should somehow better inform people - but I think we've used phrases, John, like "fragmented", "broken", "inefficient", "underfunded", and for actuaries and economists they're probably strong words.

MR BARBAGALLO (EF): We were hoping for "scandalous" and "disgraceful", commissioner.

MS SCOTT: Okay. Well, I'll take that on notice, David, and I'll give some further thought to it. Maybe John would be better disposed to it. Let's now see if John has some questions for you. Do you have any questions for Geoff or David?

MR WALSH: Yes, I do, Patricia. David, you talked about the need for capacity-building and workforce-building and, if we don't do that, we're likely to just end up with another - Woolworths I think you used.

MR BARBAGALLO (EF): Yes.

MR WALSH: Off the record, of course. I wondered if you could talk a little bit about the role of the sector. I think that's a critical (audio cut-out) the years will be the extent to which the disability sector, service providers and also people with a disability.

MR BARBAGALLO (EF): Well, as you would appreciate, John, you can't generalise. There are a lot of service providers in the sector which I would submit would have a very similar view to ours. Unfortunately, there are a number of service providers who are quite concerned about what might happen to them and the individuals who work for them and their future employment prospects. That's the nature of society, I guess.

In terms of their capacity to change and to capacity-build, it's obviously a direct correlation with available resources, and traditionally, as far as I understand it, this sector is not well served in that area. I know from the efforts we've put in at Endeavour that there's so much work to be done in terms of - you know, if I was a family member and was entrusting the support and care of my family member, I'd be expecting to see highly qualified people; dedicated; I guess a bit like the nursing system in our hospitals. Well, that doesn't actually exist in the disability sector.

So what have you got to do to fix that? You need government regulation, you need oversight, you need career planning, and this isn't in our sector at the moment. If we go to an individualised funding model, I think you will have a whole lot of people with power over their dollar but with not a lot of choice.

MS SCOTT: David, even though it's late in the day, I'm going to just challenge you on a few points. We've got regulation of the nursing sector, we've got training of the nursing sector and so on, and you know we have an insufficient number of nurses actually in our hospitals, so why are you so confident that the focus on regulation and training is the solution and not things like wages, terms and conditions, the attitude of the public towards the caring profession, the status of the caring profession in society? What you've given me is a recipe that people have applied to the nursing field for 100 years and we still have got shortages. We have more people trained, I think, in nursing that leave relatively quickly after completing their training, so I wonder if training is actually the answer.

MR BARBAGALLO (EF): Perhaps my choice of nursing was a bit ill-advised. I don't think there's necessarily cause and effect there. As you know, causation and correlation often sit side by side. Distinguishing what causes the other is the challenge. I think that obviously wages and career prospects and career opportunities are all part of that picture.

I'm not sure I would single out regulation, but we do have a cultural disposition - whether it's because of our convict start-out - whenever we see a problem, to move to regulation, I guess. We do have disability standards and I think my reference to Coles and Woolworths was about saying, "Well, okay, if you move just to an individualised purchasing model and let the market determine what happens, that's fine," and this plays to people's perceptions. But Coles and Woolworths may not be such a bad outcome if you're thinking about Bi-Lo and Aldi; if you appreciate the subtle differences - or David Jones and Myers. It's just what sort of model we can afford as a nation and what are the constructs that will deliver that.

But I have to say this: from what I observe now, we are employers of last resort and I don't think we should find that acceptable and we need to address how we deal with that - obviously wages, career paths and all those things, but someone has to pay for it obviously - and if the NDIS injects more money into the system, then I think that those issues will sort themselves out in an economic sense.

MS SCOTT: John, we've lost picture but I know you're still there. Do you have any further questions for Geoff or David?

MR WALSH: I'm back again. Yes, just one more. We've heard a lot today, Geoff and David, about (audio cut-out) the model from a service provision top-down model to a bottom-up model. The service provision is almost as the last resort, so the person's needs are met to the extent they can be.

MR BARBAGALLO (EF): Yes.

MR WALSH: (audio cut-out) services, and the service provider comes in to, if you like, put a safety net framework around that better model. Do you have any comments about that?

MR BARBAGALLO (EF): Unfortunately, John, you broke up a little. But if I understand, the tone of your question was, at the moment we basically end up with this one-model-fits-all. We end up with a distribution of scarce funds across too wide a scope and therefore almost no-one's individual needs are met as individuals. Their individual needs from time to time might be met but it's not person-centred and it's not focused around them. By moving to a bottom-up approach where the individual has choice, as proposed by the draft report, and some say over the services that they get, it remains to be seen as to whether the market effect of that will be an increase in the sorts of services that families are looking for and can afford in this model. That remains, I guess, a question.

You've posited a figure of around $6 billion, based on submissions and your analysis of the hours of need that are there. There's significant comment in the disability sector that you may have undershot that mark and I guess we fall into that category. Well, $6 billion applied differently with the other $6 billion, and more efficiently, might actually go a long way towards improving the current system beyond what we have now obviously, but whether it causes at the margin this sort of scattering of insufficient money across a group where almost no-one's needs are met, I can't comment. That's a danger, but we think the proposal to date is a good step in the right direction.

MS SCOTT: David, I want to just explore that a little bit more.

MR BARBAGALLO (EF): Yes.

MS SCOTT: The $6 billion we've suggested is a doubling of current funding. You can take your organisation or you can take others if you wish, but if you received a doubling of funding, wouldn't that be a substantial opportunity to vastly improve services? Well, actually probably better: we actually are talking about moving away from block funding. So if you've suddenly found that the clients that you serve had packages that are twice the size of either the current packages they've got or the block funding you receive, wouldn't that enable you to vastly improve the services you offer? I mean, your last statement seemed to suggest that it wasn't clear that we'd get an improvement in services out of it.

MR BARBAGALLO (EF): Because - if you remember what I said - some people are questioning the numbers that have been put into the equation, Patricia, and this is the issue. If it was just the number that are currently in the system and it was doubled, of course it would improve it. But if there's the same number of people outside the system as there currently is in the system and they all got the same amount of money, which is manifestly inadequate to support their needs now, you can appreciate where I'm coming from.

I don't suspect there's the same number outside, it's obviously some amount, so the current ones will get some increase but it won't be a doubling, and then it's the issue of what is sufficient and adequate for a person's rights and human needs to be met in a disability system in this country, and that's essentially both an economic and a political values question. What are we willing as a community to tolerate? You're not proposing a Rolls-Royce model - you're not even proposing a Volkswagen model, some would suggest; it might just still be a scooter - but this will all come out in the wash and, as I said right at the beginning, a very positive report, heading in the right direction. Doubling of funding seems like a damn good start and, if it's based around a person's needs and it's always based on a person's needs, then the amount of money available will grow according to the need, not according to some criteria that a service provider imposes, virtue of the hand of a bureaucrat or however it might occur.

MS SCOTT: Okay. Thank you for the clarification. John, are we finished with these - - -

MR WALSH: Thanks, David; thanks, Geoff.

MR BARBAGALLO (EF): Thank you.

MS SCOTT: Now we've got Bronwyn first, then Morrie, then Nigel and then Wayne. What if we give each of you five minutes? Would you like to come forward now? Okay, John, we've got four customers who would like to talk to us for five minutes each. For the purpose of the transcript, would you like to identify yourself please and then just say what you'd like to get on the record, please.

MS POLKER: My name is Brownyn Polker. This is my sister Megan Young-Smith. I'm not very good at this. Megan was in Darwin with my mum up until May of last year - my mum is rather old and frail now - and her needs were not being met. I went up to Darwin and brought them down because when they were living here before, my sister was on an individual package of $95,000 per annum plus 85 per cent of her mortgage. She's been in care - 90 per cent of the time anyway - since she was about six. She has Angelman syndrome. She has multiple disabilities and some are quite mild to moderate; some are severe to profound.

I looked after my mother and Megan for six months until I was able to place my mum. It took 10 months for me to be able to access a five days a week program for Megan, now from 9.00 till 4.00 Monday to Friday. Disability Services actually told me to find their files because they could not find them. I happen to be a registered nurse. I'm not on the workforce; I'm one of the so many thousand that are out of the workforce right now.

MS SCOTT: I see. Yes.

MS POLKER: Because of caring for my mum and my sister. So I found their files, because they couldn't find them - they were archived - and I've been told since September - and they fluffed around with this for four months and September came and September went and they told me there are no more individual packages. Megan's funds had been transferred to block funding, in the Territory, and could not come across borders. So Megan has no funding. Megan is looking at no funding. I am looking at no work. I'm looking at losing my car or my house or my sanity. I just had to give back my place in the masters program at Griffith this year.

I am 60 years old. I have a couple of little health problems: cardiac, lung, gut. Megan is 45. She is quite healthy, other than a few physical problems. I'd like to see her in some situation where - like, there is nobody else in Queensland. My brother is in Darwin. I have a 13-year-old niece; she has quite severe cerebral palsy. So I'm the logical one. Megan has another sister. She has lived overseas for 17 years. I think she doesn't come home because she doesn't want to see herself in this situation.

Without some sort of national disability situation, how many people are in a - I wonder if I'm ever going to get back to work, and just where we're going to, what we're going to do, because if I have to sell my house, then we turn around and we're -

I don't know.

MS SCOTT: So the Queensland government at this stage has provided you with no services?

MS POLKER: They have put me onto the day service that - - -

MS SCOTT: So this is the - - -

MS POLKER: She has block-funded. She's been there about a month now.

MS SCOTT: So this is the five days, 9 am to 4 pm?

MS POLKER: Yes. Prior to that, with another service, she was getting nine hours a week, and DSQ came up with another three hours of funding through some other little road. There are so many little roads and things that they - yes.

MS SCOTT: So many different packages?

MS POLKER: There's nothing holistic. There's nothing that plans. They have offered me respite. Megan has been, as I say, in institutions. She's been in the Gladesville Retardation Centre, which was attached to Gladesville Psychiatric Hospital, from about 11 to 13. She went from there to Stockton Retardation Centre in New South Wales. I hauled her out of there when she was 16 because I couldn't stand it any more; and my mother was overseas. From there she actually got into group homes in New South Wales. So my mum has moved around a bit with her. I don't know if I actually would have brought either of them down had I known that this scenario was going to happen, you know?

MS SCOTT: You never expected there to be so - - -

MS POLKER: No, and I had not planned for this. I financially had not planned for this. All of my savings have gone this last 12 months. I'm paying a mortgage on a carer's pension.

MS SCOTT: Yes.

MS POLKER: I also run a car, two phones; I've got contracts for all these things. It would cost me more money to cut the contracts than to keep sort of struggling along and borrowing from everyone, including the government, and it's very demeaning; it's very demoralising. I make a very good income when I'm working. I work very many hours. I've worked since I was 14 and I've nursed since I was 17. That's 43 years of nursing. I just don't know, but I think something has got to be done. There's got to be more people than me and Meg sitting out there floundering, and we are floundering.

MS SCOTT: All right. Thank you. John, any questions for Bronwyn?

MR WALSH: No. I think it's pretty clear.

MS SCOTT: Thank you very much.

MS POLKER: Thanks for your time.

MS SCOTT: Thank you.

MS SCOTT: Morrie, please. Could you give your full name, please, Morrie?

MR M. ROWE: Thanks, Patricia. I'm Morrie Rowe. I'm here as an individual. I have twin four-year-old grandsons who are autistic. One of the points I wanted to make - and it has been partly made in the report - is they were diagnosed about 16 months ago. While they're not severely autistic, they don't speak at this stage, and their development is very slow. We've been able to get them into specialised education over the last 12 months, which is extremely expensive, but with our help we'll be able to sort of fund that, but it's out of reach of the average person in society.

My point is that there's a view, with early intervention with children up to the age of seven, if you put a lot of money into a given therapy, which they're getting every day - six hours a day - then you can get good outcomes, and hopefully these children get into mainstream education, which means they will come through to the end of the education process and hopefully be able to get gainful employment. If they don't, they will struggle through education, they will come out the other end and more than likely be underemployed and/or completely dependent on welfare.

The point is investing money up-front will be saved down the track. These people would be on welfare for 30 or 40 years - and I think that's partly made in the report. I just want to clarify. You mention in the report "autism" - it's mentioned a couple of times - but in the terms of reference it talks about "severe or profound disabilities". Is there a scale of these things? I mean, autism can be severe or mild. So is autism generally accepted as a disability for the purposes of this review by the commission?

MS SCOTT: John, if you want to answer this question, feel free, but are you comfortable if I have a go?

MR WALSH: You can go first, Patricia.

MS SCOTT: Okay. You are right, Morrie, that our terms of reference use the phrase "severe and profound". As we explain at length, in the report - but I appreciate you are a busy man and you wouldn't have had a chance to get through the 800 pages - "severe and profound" is linked to how the Australian Bureau of Statistics asks certain questions. We didn't find their definition particularly useful, to be frank, because a person can have a significant intellectual disability but they may be able to speak, they may be able to walk, they may be able to dress themselves, they may be able to toilet themselves, but they might not be able to make a decision that's complex, they may not be able to cope with changing circumstances, they may not be able to appreciate danger or understand risks or be able to form friendships or have networks or be employable or whatever.

MR M. ROWE: Yes.

MS SCOTT: We ended up looking at other eligible criteria rather than severe or profound, and we identified four categories, and we used assistance with functions of mobility, communications, we used intellectual disability, we used early intervention, and we specifically mention autism in that category.

MR M. ROWE: Yes.

MS SCOTT: Then those ones that couldn't be quantified, but where it would be apparent that assistance would mean that people received the care they need that would throw them into other systems, like for example hospitalisation. So we do mention autism. I don't think I'm able to say that absolutely every person on the spectrum would be necessarily in receipt of a package, but we do say that autism is an example of a group that would benefit, for example, from early intervention.

MR M. ROWE: Yes.

MS SCOTT: You may well have a person severely autistic who has problems with communication skills, problems with making decisions and so on. That's why we talk about a need for individual assessment. So I can't give a blanket thing. It's a bit like saying that every person with cerebral palsy would get the same level of package. That wouldn't be the case. Assessment would be based on individual needs, and of course the levels of natural support that they receive. John, are you comfortable with that explanation?

MR WALSH: Yes, that's my understanding, Patricia, as well.

MR M. ROWE: I guess that leads on to one of your recommendations, which is 4.4 on page 48, which says that people should pay the full cost of services, primarily therapies, for which clinical evidence of benefits are insufficient or inconclusive. I guess that's what you're alluding to by saying, "Well, there could be a scale, if the services aren't considered sufficient or conclusive." Is that what this meant?

MS SCOTT: No. Actually, what we were talking about there, Morrie, is that some people have advocated dolphin therapy.

MR M. ROWE: Okay.

MS SCOTT: Some people like aromatherapy.

MR M. ROWE: I see what you mean.

MS SCOTT: Some people like music therapy.

MR M. ROWE: Yes.

MS SCOTT: Some people like - I'm sorry, I've forgotten what you call it - when you have little drops of substances in large quantities of water which is then diluted down and down again. We're conscious that people (indistinct) to a number of therapies, a number of alternative approaches, and the point to make here is that there would need to be clinical evidence that those particular therapies work.

Now, we're conscious in the area of autism that there are a number of expensive therapies working. We're not saying that they're not appropriate. All we're just saying is that the commission hasn't got the time to look now at identifying what are the right ones and what are not the right ones, but it would be the role, if the proposal got up, for the organisation to carefully look at those therapies. It would have the advice of professionals in that field to ascertain what were the appropriate therapies. That's what we're talking about. Think of it as dolphin therapy.

MR M. ROWE: Yes, okay. No, that's okay. They're going to a recognised school that's got the right sort of therapies and so forth that have been approved. Thank you very much for your time.

MS SCOTT: Okay. Thanks, Morrie, for coming along and hearing from you today.

MS SCOTT: Okay, Nigel, I think you're back for a further comment. Nigel, could you just state your full name, just for the record, please.

MR WEBB (QDN): Nigel Webb. I stated earlier that I was representing the Queenslanders with Disability Network and in part I'd like to continue that representation. Thank you for the opportunity to come back and briefly address a few points. I've really enjoyed staying today. I had originally intended only to come and make a representation and then quietly exit, but I've learnt a lot from being able to participate - well, being able to listen to what people had to say today, so thank you for that.

Three quick points. You asked earlier today a question of one of the participants: what role does government play in all of this? My strong suggestion to the commission and to the public is that government at all levels, along with the community, has a very clear role in attitudinal change. If we want employment systems to work, if we want accommodation systems to work, if we want transport systems to work, for people with disabilities and their families to be able to fully participate in the community, there needs to be a very strong emphasis on the roles of government at all levels about attitudinal change; whether that means we create infrastructure that people with disabilities and their families can access, whether it means that we make things easier by example - the Australian government actually employing people with disabilities and setting benchmarks and opportunities for those things to occur; but leading by example and really being a driving force in that attitudinal change, and I'd encourage the commission in its final report to look at how they can get involved in some of that, or certainly the Queenslanders with Disability Network will reinforce in our final submission how they can look at opportunities to do that.

Secondly, I'd like to make some observations in regard to some things that other people have said today about block funding and the issues around block funding, how it can discriminate about how people have access to services or receive their services, or the expectations are not being met about how those services occur. My personal way of dealing with this and thinking about this is that block funding is literally vacancy coordination by another name. Okay, so a person enters a service, they have a quota system to deliver X services to people, and that person leaves, dies, whatever occurs, and then another person is just simply backfilling the position. The question then becomes: does the organisation or the individual have the resources to meet those ongoing needs for that person?

So that is a significant issue, because this notion of vacancy coordination has been certainly occurring in the Queensland context for the last 10 to 15 years. So you're just placed because there happens to be a bed and four walls, and someone who may or may not care about you, which is a bit of a worry. It's basically an institution on a smaller scale. So I have some real issues with that and we really need to address how we're going to deal with that.

The last issue I'd like to talk about is, again, something I mentioned a little bit earlier this morning and David Barbagallo picked it up nicely. It's about capacity-building. When we're setting up the NDIS as a framework, we need to be able to say, "How do we address unmet need and also undermet need?" There's a whole lot of people out there who have individualised or block-funding packages now that don't necessarily address their fundamental need or their aspirational need, depending on how you want to measure it, so that's going to be an issue which will distort figures and all sorts of things. So if you commit an additional $6 billion, does that actually address the unmet need that we experience or the undermet need that people experience? If I can be so bold as to suggest that there's probably another $6 billion that's required to look at some of those other areas of work.

How palatable that will be to the Australian taxpayer and the community, of which I am one of many, will be an interesting question and we need to get that message out to the community and transpired by government; and if we can look at how some of the modelling is done to do that - and there are some good examples in some other parts of the world that I'm sure more profound people than me will reference to address that question. So those are the three points that came out of today for me. So I just wanted to put another perspective, or my perspective, on those topics.

MS SCOTT: Thank you, Nigel. Any questions, John?

MR WALSH: No. Thanks very much, Nigel.

MR WEBB (QDN): Thank you.

MS SCOTT: Nigel, we are going to be putting some more appendices up on the web site and one of those looks at a lot of material from the US, from their experience, and the idea that you improve services and then more people come out of the woodwork, called "the woodwork effect". Some overseas studies suggest that it is manageable and it isn't large. Now, we haven't got a lot of experience to draw on from Australia, but you might take some comfort from that.

MR WEBB (QDN): That's good.

MS SCOTT: You might want to look at those references when they become available.

MR WEBB (QDN): Excellent.

MS SCOTT: Thank you very much, Nigel.

MS SCOTT: Now we'll have Wayne, please. For the record, please, your name and whether you're representing yourself or an organisation. Thank you.

DR SANDERSON: Wayne Sanderson. I am representing myself here today. I do want to indicate, however, that I serve currently as chair of the Health Community Council of the Royal Brisbane Women's Hospital. I do not work for Queensland Health. I am in no way authorised or seeking to be authorised to express any views on behalf of Queensland Health. It's a statutory position, it's independent, it reports directly to the minister, and we have the power and the responsibility to give advice to the CEO of our relevant health district, which we do.

One of my concerns, which is shared by many in my council, across the last 12 months in particular, with health reform, system reform and funding increases of various kinds on different merry-go-rounds all happening, and the total bamboozlement of many, many people, including us much of the time - one of my concerns there has been how does the disability frame of reference connect with whatever we're going to end up with in our public health systems? We in Queensland, of course, have had a lot of turbulence even before the national reform process got started; turbulence in terms of rapid population growth in eight or nine regional centres as well as in the metropolitan area of Brisbane.

However, it is noticeable to us that when we look at the very specific question of coordinated care and continuities of care for people who are living independently in the community with quite high levels of disabling conditions to deal with - I think especially of the chronic neurological conditions, that whole family of diseases are progressive, and the difficulties that people have maintaining independent living there - we are aware that some of the NGOs, some of whom have had block funding from Disability Services Queensland - several haven't though - have been able to negotiate and plan and design, with Queensland Health, in several regional centres, shared care services for - let's say they're neurophysio, physiotherapy, maintenance. This is crucial if you're trying to live in the community and you've got a progressive neurological condition.

Those work. There aren't enough of them. They work because certain NGOs came in the door, with Queensland Health district managers, and didn't come empty-handed - brought money with them. So there could be shared costs in these things. There could be upgrading of staff and expertise and access and time, and all these things.

Now, I'm saying all this here just to put a bit of a specific point to this question of how will we travel with an NDIS which I'm optimistic about, eventually. I think it's going to be up to us, by the way, politically, in the community. We've got to fight the battle out there on this and tell the truth, clearly and persuasively, to a whole lot of people.

Let's assume it happens. The coordinated care issues alongside the big, complex and "dreadful to deal with in a lot of ways" public health systems - enormously challenging. So I want to encourage the commissioners and all who work with you to be very mindful of that. Of course, with all the doubt and difficulty we have at the moment, we don't have firm conclusions on how a lot of these public health arrangements are going to work out. Please encourage, through your work, the decision-makers to take a very positive account of these things and to reap the benefit, where possible, of intelligent and resourceful partnerships with not-for-profit organisations in the community.

MS SCOTT: Wayne, just before you go I wouldn't mind setting a small amount of homework for you. Given that you've got a real-life example of somewhere where the partnership arrangements have worked effectively, and that adults have been able to work out that an optimal outcome involves putting two buckets of money together, we would love, or I would love to see - John, would you be comfortable to see - - -

MR WALSH: Yes, I'm nodding my head, Patricia.

MS SCOTT: Great. It would be great to be able to use a real-life example. You'll see in our report that we try and give examples of where things work and where they don't work. If this is something that you could just provide us a short amount of material on, and maybe a contact number, we'd certainly very much welcome getting it.

DR SANDERSON: Yes.

MS SCOTT: All right. Thank you very much. Without any further ado I now adjourn the hearings, and they will resume here tomorrow at 11 o'clock. Thank you very much for your attendance today. It's very much appreciated.

MR WALSH: Thanks, Patricia.

MS SCOTT: Thanks, John.

AT 4.43 PM THE INQUIRY WAS ADJOURNED UNTIL
TUESDAY, 12 APRIL 2011