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TRANSCRIPT OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT SYDNEY ON MONDAY, 19 JULY 2010, AT 9.33 AM

Continued from 19/7/10 in Brisbane

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MS SCOTT: Good morning, ladies and gentlemen. Welcome to the public hearings for the Productivity Commission into disability care and support. Thank you for attending today, and I appreciate that a number of you have travelled quite a distance to be here. My name is Patricia Scott and I'm the presiding commissioner for this inquiry. My fellow commissioners are David Kalisch and John Walsh, and it's good to have John here today.

The inquiry started in April, with a reference from the treasurer. The Australian government has asked the Productivity Commission to examine the feasibility, costs and benefits of a national disability scheme that would provide long-term essential care and support; manage the costs of long-term care; replace the existing funding for those covered by the scheme; take account of the desired and potential outcomes of each person, over a lifetime, with a focus on early intervention; provide a range of coordinated support options, including accommodation, aids and appliances, respite, transport, day program and community participation; assist people with disabilities to make decisions about their support; provide for people to participate in education, training and employment where possible.

The Australian government has asked the commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. We have already talked to a range of organisations and individuals with an interest in these issues and have held hearings in a number of capital cities. We released an issues paper in May. We are grateful for the submissions already received, and submissions can be downloaded or viewed from our web site at www.pc.gov.au.

We would like to get submissions in as early as possible, with a view to examining those in our considerations, but the commission has extended the due date for initial submissions to Monday, 16 August 2010. The commission welcomes second or even third, fourth and fifth submissions. These submissions may include additional points people wish to make, comments on other submissions and the results of community consultations.

The purpose of these hearings is to provide an opportunity for interested parties to discuss their submissions and their views on the public record. We would like to conduct all hearings in a reasonably informal manner, but I do remind participants that a full transcript is being taken. For this reason, comments from the floor cannot be taken. But at the end of today's hearing I will provide an opportunity for anyone who wishes to make a brief presentation. So if you have been in the hearing all day and wish to make a comment, even a brief one, I will invite you at the end of today to come forward if you wish.

Participants are not required to take an oath but are required under the Productivity Commission Act to be truthful in their remarks. Participants are welcome to comment on the issues raised in other submissions, and that usually happens, people come forward and say, "I disagree with the last person," or "I agree with their position." A transcript will be made available from the commission's web site following the hearings. Are there any media representatives in the audience today? No. Thank you. Because we are making a recording so that other people can read about our proceedings here today, I'd be grateful if you'd take the time now to turn off your mobile phone or to put it on to silent please.

To comply with the requirements of the Commonwealth occupational health and safety legislation, you are advised that in the unlikely event of an emergency requiring the evacuation of this building to please follow the instructions of the hotel staff. If you require assistance at any time during the day, please see Hudan, at the back of the room, who you may have already met or spoken to over the phone or email, or please approach me, and John. I'd like to welcome Slater and Gordon and ask them to come forward and present their evidence. Thank you. Good morning.

MS BOOTH (SG):   Good morning, Commissioner Scott and Commissioner Walsh.

MS SCOTT: You have approximately half an hour. Thank you for the material in advance of today. Just state your name for the record, and if you'd like to make an opening statement, please proceed.

MS BOOTH (SG):   Thank you so much, Commissioner Scott. I'd like to introduce myself, Anna Booth. I chair the firm. I'd also like my colleagues to introduce themselves. Our intention would then be for myself to make a few opening remarks and then to invite two people who are associates of our firm and through whom really the points that we wish to make and continue to elaborate on when we make our written submission can be made far more compellingly, frankly, than we can make them. As I said, Anna Booth, chair of the listed law firm Slater and Gordon. Genevieve?

MS HENDERSON (SG):   My name is Genevieve Henderson. I'm a practice group leader with Slater and Gordon. I have worked in personal injury litigation for more than 20 years and I have face-to-face contact with people who have acquired disability through motor vehicle accidents and other accidents.

MR STEPHENS (SG):   My name is Hayden Stephens. I am the general manager of the personal injury group in ACT, New South Wales and Queensland. My role is to oversee the personal injury practice groups, of which Genevieve is a member of one, throughout those states and the territory. My role has expanded recently to become activity involved in assisting governments and lobby groups with legislative reform, most recently with the Hanks inquiry in Victoria, and even more recently with the Queensland legislation reform that was undertaken just a few months ago. I suppose in that role what we do, through the exposure of Genevieve's work and others' work in our group, is have a sense of the tensions involved in these debates, particularly in legislative reform at the coalface.

MS BOOTH (SG): Just in a practical sense, of course the key thing that we want to do here today, commissioners, is begin our engagement with the Productivity Commission. Of course it's the beginning of something that will take place over several months. We want to spend most of our time that we have been allocated here this morning taking questions from you. So in fact, contrary to what we have just decided, it might be good if Genevieve and Hayden can remain at the table so that they can take questions from you. But perhaps also, just to get settled, we could ask Cheryl Koenig and Karen McEwen to join us at the table now so that when I have just made a couple of framing remarks, we can hear directly from them. In fact that does work in terms of what might assist us with that process.

MS SCOTT: You might just need another chair or so.

MS BOOTH (SG): I'm changing the ground rules. We decided we'd vacate, but as I think about it - - -

MS SCOTT: We're flexible.

MS BOOTH (SG): Thank you.

MS SCOTT: Welcome to the table.

MS BOOTH (SG): That will work. Thank you very much.

MS SCOTT: We might just have your name, for the transcript, please.

MS KOENIG: My name is Cheryl Koenig. I am an author of three books relating to disability, in particular brain injury, and I was 2009 New South Wales Woman of the Year for my work with people with disability and carers. My most important job, however, is that of being a carer. My son was hit by a car 13 years ago.

MS McEWEN: Karen McEwen. I am the mother of Alex McEwen, who has Down Syndrome, and I am also a high school teacher.

MS SCOTT: Thank you.

MS BOOTH (SG): Thank you so much, commissioners. As I said, this is the beginning of our engagement with the Productivity Commission. We have prepared a short three-page overview of the major themes that we intend to develop as we write our submission to you. So we don't want to use our time this morning by reading to you words that are already on paper. For anyone in the audience who is interested in our themes, I have some spare copies to give you. We certainly intend to meet the deadline, although we'll probably just meet it, commissioners, because we're doing a major piece of research to support our submission.

What we decided as a firm to do in light of the fact that as a firm of long experience in the area of disability, 75 years of supporting particularly those who have experienced accidents either in the workplace or in other parts of the world, and more recently as a firm with a growing practice that involves the establishment of disability trusts and testamentary trusts for families of people with disability, however acquired, but particularly acquired through either injuries that do not provide legal recourse or through congenital means. Our experience with our clients over a long period of time causes us to have approached this I think slightly differently than perhaps many law firms might, and that is from the source of the concern, from the people with disabilities themselves.

That is why Cheryl and Karen are here today to talk to you rather than us. The real theme that you'll see developed in the principles that we have developed on which we are going to base our submission and that will be developed in our submission is that we sincerely believe that this is the area of public policy that has been neglected, ignored, has put the onus on the people with disabilities and their carers and advocates to take the initiative to sometimes frantically and desperately seek our help from whatever source of the myriad sources from which fragmented care and support is available.

We are absolutely committed to your course, which is to take a coherent look at this area. We sincerely believe that there are gaps in the provision of support for people with disabilities, however acquired. We are also very familiar with the system that does exist. To be colloquial about it, I guess the key thing that we will be bringing forward to you and justifying, I believe, with our empirical work that we're doing to support our submission, is not to throw the baby out with the bath water. We see real gaps that need to be filled.

We also believe that there are some good systems that are currently available and that they should be available to a wider range of people, that the source of disability, the severity of disability and the state within which one resides should not determine the level of care and the quality of care and support. So that will come forward in our submission. That's where we're coming from, and it's for that reason today that we asked our associates to come along and really speak from their own lived experience, which as I said at the outset is far more compelling than any view we could give mediated by a legal frame. So Cheryl, I might ask you to have a bit of a talk to that theme.

MS KOENIG: Okay. As I said earlier, my son Jonathan was hit by a car when he was 12 years old. With the help of a firm like Slater and Gordon we had to pursue litigation and we were successful. That gave us then a lump sum payment, one of the last few lump sum payments before lifetime care and support came in. Personally speaking and from our family's experience, I believe that the long-term cost of disability support services could be reduced if the intensive early intervention recommended by doctors in Melbourne and overseas were to be implemented as part of a national reform to service provision.

Having the money that we received in a lump sum payment enabled us as a family to pursue this type of intensive intervention that we were unable to get in this state. It's our belief, and it's now the belief I think across the world that neuroplasticity does exist and that there is no expiry on the improvement of brain function or the repair of a brain. It's also my belief that the worst catalyst for feeling helpless is feeling powerless. I believe that, given choice, families are given power, and it is all about choice I believe, because I don't think there is any one best fit for every individual family.

I would not like to have been in a position where I had to have a case manager and apply for different services and equipment and have that long drawn-out process. That would not have helped Jonathan get where he is today. Currently he is not a burden on welfare, he works in four part-time jobs five days a week and he is learning to drive a car. He participates in life, although at a different level than he otherwise would have. Thank you.

MS SCOTT: Cheryl, just before we turn to another person, is it okay if I ask you a few questions?

MS KOENIG: Yes.

MS SCOTT: Some people tell us that one of the disadvantages with the common law approach is the length of time before cases go to hearings and then waiting for judgments. How long did you have to wait in the case of your son Jonathan?

MS KOENIG: It was about seven years.

MS SCOTT: In that time were you able to get rehabilitation starting? I mean, you've talked about the importance of early intervention. Was that something that you were able to commence straightaway?

MS KOENIG: Only because we were as a family committed to doing it. My husband gave up work and we worked 10, 12 hours a day ourselves on therapy, because we couldn't get that kind of intensive intervention that I've written about.

MS SCOTT: Thank you very much.

MR WALSH: Cheryl, I suppose I'm interested in how you think it would work in the situation where you were able to access that early intervention immediately, just by nature of the severity of the injury and that that were provided in a no-fault environment for everyone who had those injuries.

MS KOENIG: It's difficult to say because every injury is so different, but I do see it making huge difference, it has got to. There's compelling evidence right around the world now that early intervention and long-term intervention and intervention at any stage, actually, five to 10 years after a severe brain injury can make significant improvement.

MR WALSH: I'm also interested in your comment about that you appreciate having control over the funds.

MS KOENIG: Yes.

MR WALSH: I suppose one of the things that we've been hearing in other hearings is that people are advocating self-directing funding and self-directed management. So I'm interested in your response of how you would feel if you did have that sort of situation. So rather than getting a lump sum seven years after the event that you started to get packages of money on an annual basis or six-monthly basis that you could then control and manage the care of your son, and so the risk of the lump sum running out was taken away.

MS KOENIG: I think the key word is "control". That, to me - you know, that's the emphasis there. I think that would work as well. I don't know - I can't say which one would work better for us but definitely being in control. I know there's some families that are not in a position to have that ability to make decisions and so therefore need to be under the care of a case manager or a bureaucrat. But I would say that the vast majority of families are able to make the right decisions for their person that they care for. So having control, again, is having power and feeling useful.

MR WALSH: Thanks.

MS SCOTT: Thank you.

MS BOOTH (SG): I just want to ask Karen to say a few words now because of course, as I said, there are gaps in the system and one of the big gaps is where there is no legal recourse, particularly in the case of people who were born with a disability, the kind of support that Cheryl has been able to have her family avail themselves of is not there. So let's hear from Karen.

MS McEWEN: My daughter Alex was born in 1991 and at that time, in terms of Down's syndrome, there was early intervention available. I suppose just tapping into one of the themes that Cheryl sort of mentioned in her talk was the significance of early intervention in terms of a disability which is evident at birth. I suppose extrapolating from that after a disability is acquired intervention is key. One of the difficulties is that intervention is fairly - at times difficult to get. It may be quite costly; because of the numbers of people trying to access it, it can be just simply hard to find. Luckily for us we were actually able to network our way into an intervention program.

I suppose the main point I'm concerned to make is that my daughter has a moderate intellectual disability. As a result of some pretty impressive schooling she is literate and numerate and has reasonable skills, albeit a significant speech difficulty, which means that her expressive language is poor. So she is by no means indicative of an individual with Down's syndrome because like all disabilities there's a range. She's currently in a transition to work program which is operating through Centacare. I suppose the prognosis is that she will probably access some sort of supported employment at the conclusion of that program.

Our concern as a family is that we don't see the problem for Alex in terms of simply providing her with bricks and mortar, so to speak, but to ensure that she has quality of life and that she is actually able to make a contribution to society, that what she will need long term, and given her health I think long term will be decades, that she will need some sort of carer assistance in terms of just daily organisation, so that executive function will need some sort of assistance. So our concern is whilst we're young and - well, relatively - and happy to have her with us and so on, that we're - the concerns that we have is as we age that she will not predecease us and what will happen. Her brother also has a disability. He has Asperger's syndrome, so he has his own sort of suite of difficulties. But certainly her limitations mean that it would be a great tragedy if she didn't have that ongoing support in, I suppose, some sort of group home-type model with sort of care, because as we know the cost is not, as I said, the accommodation, the bricks and mortar. The cost is really the human resource element. So that's sort of where I would see her requiring assistance down the track.

MS SCOTT: Thank you.

MR WALSH: Yes, thanks, Karen. I have a couple of questions. The first is in respect to Alexandra, is it?

MS McEWEN: Yes.

MR WALSH: Alexandra's early intervention.

MS McEWEN: Yes.

MR WALSH: We've had a couple of submissions around early intervention with respect to autism spectrum disorders, so have a little bit of feel about what that's about, but haven't heard a lot about the early intervention with respect to Down's syndrome. Could you talk a little bit about what that looks like and how much it costs?

MS McEWEN: Okay.

MR WALSH: When it starts, what age - - -

MS McEWEN: Yes. Alex started early intervention when she was two weeks old. I suppose one of the advantages of Down's syndrome is it is diagnosed at birth. So unlike disabilities such as autism - my son, for example, was diagnosed at four - you do have that advantage of being able to tap into early intervention early. We accessed it through Macquarie Uni before it was subsequently defunded. But what - the premise of the early intervention was that - looking at the various array of skill areas, gross motor, fine motor, receptive and expressive language, social skills and so on. That looking at what were normal milestones it was ensuring that children actually - with Down's syndrome, and there were children without Down's syndrome but with some sort of intellectual disability - were actually quite proactively taught towards the acquisition of those skills, not leaving the acquisition to chance as per the normal population.

So Alex did that until the age of four. She then actually had been to preschool as well as early intervention. She accessed an early school program through a special school, SSP Cromehurst at Lindfield, and preschool and then from there went into a unit at a public school for children with a disability, intellectual disability, moderate to mild. From there she went to a private special ed high school. So that's sort of basically the background. But I suppose the advantage with Down's syndrome, just to reiterate, is that because the diagnosis is at birth you can actually start promptly with the early intervention. That is problematic in other disabilities just due to diagnosis, diagnoses difficulties.

MR WALSH: Do you have a view on the relative merits of the special education high school versus mainstream high schools?

MS McEWEN: Yes, that's a really interesting issue. We always argued that we weren't prepared to sacrifice Alex on the altar of integration. I think it really is a case-by-case issue. I think people need to reflect on the level of ability of their child, what their particular needs are. We had made an application to a private school which actually had a unit in it and at the eleventh hour that placement didn't materialise. I suppose it's really dependent upon the skill of the educators. I think the challenge for a special ed high school is that they have to facilitate that integration to take place in other ways, which this school did.

The advantage of a special ed high school is that you are core to the school, you're not marginalised, you're not the pariahs, which I think is what often happens in a mainstream high school. These are the kids that are - - -

MS BOOTH (SG): You've got that experience.

MS McEWEN: Yes, we know about that, Anna and I. With our children we know about that issue.

MS SCOTT: Sorry, I didn't catch Anna's comment.

MS BOOTH (SG): Sorry, that was a bit naughty. I was urging Karen to make the point to you that she has both experiences, so has had one special needs child in a mainstream setting and one in a special-needs setting and I also have a intellectually disabled child in a mainstream setting who has also been in a special-needs setting.

MS McEWEN: The difficulty is that issues such as bullying tend to happen in the mainstream high school despite the ethos of the school, despite proactive antibullying policies and so on. But it's a difficult issue and one is sort of drawn between what's going to be the best outcome for that particular child. So in a way we've actually gone down two routes with two different children and I think Alex's road was a relatively stress-free one and a very optimal one in terms of what was the final outcome.

MR WALSH: I'll hand over to you, I'll come back to it after you've finished.

MS SCOTT: No, that's fine. I'm just conscious of missing the opportunity to ask the lawyers a few questions as well. Thank you very much, Karen, for that. Because we're going to run out of time and because you've given us written material, I wouldn't mind asking a few questions of the lawyers, John, and if it's the case that you want to take them away, that's fine, we don't mind setting homework and see how people go. Hayden, I was conscious that you indicated that you look after personal injury over a number of states and of course across each state we've got different approaches to compensation arrangements and disability schemes. I guess I would be after your quick assessment of which scheme is best in terms of the outcome of the clients, that's question number 1.

Question 2, we've heard a number of times figures on the proportion of total costs for the payout that are absorbed in legal costs and I'd be interested whether there are any figures available on that across a number of jurisdictions, for example, and across different types of cases. My recollection, John, is that at one stage someone said that when it comes to medical indemnity up to 42 cents in the dollar can be absorbed in legal expenses.   I don't know if that is your experience, but I'd be interested in knowing what figures you can give us in terms of personal injury, medical indemnity, accident insurance and so on.

The third one I had was the timing of payouts and the concept of compensation psychosis. Is that a term you're familiar with?

MR STEPHENS (SG):   No, but I am familiar with you - I think I know what you mean, where a compensation claim seems to exacerbate a person's injury. Is that right?

MS SCOTT: Yes, that's the way I've read the literature, that in fact because people quite understandably need to maximise the payout and because rehabilitation is often denied them because they're not in an arrangement that provides early intervention, in fact rehabilitation is denied, they're potentially exacerbating the circumstances. I would be interested in your views, we could take some of those - - -

MS HENDERSON (SG):   I'm going to answer that last question, I'll leave you with the first two. It's certainly been my experience that that psychosis does not really exist but it has to be carefully managed by the lawyer involved and the duties of the people who are coming to me to rehabilitate themselves certainly are paramount and a well-trained lawyer will give appropriate advice about that so it doesn't actually become an issue in the claim. However, some schemes within New South Wales, which is my experience, do rely on the permanent impairment model, that's the motor accident experience. Some other schemes - the Civil Liability Act does not, that's a disability model, which is a better model in my view because it doesn't rely on a permanent disability to maximise compensation. The motor accident scheme and the workers compensation scheme in New South Wales both emphasise early medical intervention and actually early medical intervention is available in both those schemes. While Cheryl's experience might have been slightly different, in most motor accidents the insurers start paying immediately and the scheme is certainly geared in that way.

For most people, a lump sum payment, rather than being a psychosis is a closure for them. They see it as justice. It says, "I've lost something and it is valued by society. I've got something out of it. I'm not where I was before, but I've received something. I feel justified and happy after that." Certainly most people do get better. After they get their lump sum, they walk away and they do feel better. But that's not because they were feigning illness or even trying to maximise compensation entitlements, the process has come to a resolution where they feel something has finished and I think that's very important for injured people.

MS SCOTT: Thank you, Genevieve.

MR STEPHENS (SG): I think on that note I might start with the issue of claim duration. In Cheryl's case she spoke of seven years, whilst that's not rare, it would be in the minority of common law cases that would have a claim duration of that type. In most cases in workers compensation, motor vehicle schemes you can have resolution sometimes with 12 months, but usually over a, say, two to three-year period and I've no doubt that in our formal submissions we will be able to elaborate on those statistics in greater detail. It is an important issue and I think Genevieve referred to the obligation and responsibility of lawyers in the process. Certainly at Slater and Gordon claim duration is something of the forefront of our minds because the earlier we can bring resolution and closure to a person's claim, certainly the more satisfied the client but certainly in Cheryl's case and other clients' cases they're able to tend to the needs of the child or, if it were themselves, themselves

MS KOENIG: Can I just jump in there and say I think ours was protracted to that length because we were committed to rehabilitation of our son right from the word go and so it was hard for the insurers to determine his outcome because he was continuing to get better without the lump sum compensation. We committed our family - like I said, gave up work and we started very early on. So we weren't waiting for lump sum payment to come in and then suddenly getting better, we were already well on our way.

MS SCOTT: Thank you.

MR WALSH: Just on that, it's encouraging to me, Cheryl, that that's able to happen without a lump sum with the right early intervention.

MS KOENIG: It's only through extended family support really. That's what it boiled down to.

MR STEPHENS (SG): Your question to the various state schemes, you would be aware that right now in fact there is very healthy debate around the workers compensation arena and in particular harmonisation of those laws. It is quite a complex answer. Each state, as you rightly observe, has different scheme. Most are hybrid schemes where you have on the one hand common law but on the other some certain no-fault entitlements. Depending on the profile of the injury and where your injury occurred, your entitlement can vary. For example, a severely injured worker in, say, a Queensland jurisdiction would be far better off than, say, that severely injured worker in another context, for example, in South Australia, to state the extreme.

There is also a great variance in the statutory entitlements. For example, our very own Comcare scheme I think delivers Comcare workers certain handsome entitlements in that area - I say the word "handsome" in comparison to some other states. I must say even those entitlements in the context of a permanent impairment claim are relatively modest when you look at the nature of the injury that the worker has suffered. I don't wish to avoid answering your question, other than to say and to acknowledge that there are strengths and weaknesses to each of the schemes [] that we work in. Right now though I think the word of caution is that we don't have race to the bottom, that in the debate involving workers compensation that in the sake of uniformity we don't have a common scheme across all where you have effectively uniform entitlements which are of a low or base quality. What I think we should be striving for and what we're actively engaged in with various legislators in this space is saying that we should be striving for a high standard, a gold standard so that workers across every state, whether they fall within the no-fault scheme or a common law scheme, receive entitlements where they're certainly no worse off than where they are now.

MS SCOTT: I'm conscious of time, so what we might do is just another five minutes or so and then we'll make sure that the next person gets their allotted time as well. But you might take these on as exercises and analyses that you could present in your formal submission from Slater and Gordon.

MS BOOTH (SG):   We certainly will, commissioner.

MR WALSH: Yes, the next one is one that couldn't be answered in two minutes, so I'd like it if you would go away and think about it. Critical to this issue, particularly with respect to Slater and Gordon and other legal involvement in these schemes is the relative merits of a non-litigious return to work or return to function scenario versus one that's in an area of litigation. So I'd like your response around - just thinking about the injured worker or the injured motorist from the day they get injured, what would be the best intervention to get them back to work or full function at the earliest opportunity. If you would think about that in terms of medical involvement, rehabilitation, employer involvement, community involvement, legal involvement, what sort of mix of support you would see as most optimal.

MS BOOTH (SG): We certainly will, Commissioner Walsh, and in fact - I mean that's a very good point of departure just to say that the impression we wish to leave with you is that we are concerned about all people with disabilities, although we have a rich experience and we will certainly bring that to bear in our submission in relation to people who have accidents, particularly those with legal recourse. It is devastating to us to find clients who don't have legal recourse and to contemplate what their likely life scenario is when they leave our office and we have no further contact with them.

It's devastating for us to meet potential clients who might come to us quite late in their children's teens, perhaps, when they're beginning to think as carers about predeceasing their disabled children to only be able to work with the means that they have at their disposal and not to be able to access any public funding whatsoever. The fact that public funding from one source or another is available to those who have an accident with legal recourse is for us a matter that we think this commission should address, because it simply isn't right that the source of your disability dictates your quality of future life.

MR WALSH: I suppose just on that point, how would you see that legal recourse operating where there may not be any question of liability, where things just happen - you don't need to answer it now.

MS BOOTH (SG): Yes, I think that's where a comprehensive public policy framework on disability that is not dependent on source of disability and which is undoubtedly going to be multifaceted but with some kind of overriding philosophy of architecture that is nationally determined, if not necessarily nationally administered, is certainly what we are looking forward, really, to the commission building. We want to support you along the way in bringing to bear our experience to see whether we can together actually build that kind of framework for Australia.

MS SCOTT: Well, thank you very much for your testimony. Thank you for coming along, especially to Cheryl and Karen and to Slater and Gordon. Thank you.

MS BOOTH (SG): Thank you.

MS SCOTT: I now welcome to the table Sean Lomas from Spinal Cord Injuries Australia. Please come forward. We do have tea and coffee, don't we, in the back room. So if you'd like to, during the little breaks, grab yourself a cup of tea or coffee that's good. We'll be having a formal tea break at 11 o'clock. Welcome to you both. For the record could you state your name and your organisation please and then would you like to make an opening statement?

MR LOMAS (SCIA): Just a very brief one.

MS SCOTT: Yes, sure, and then we might ask some questions.

MR LOMAS (SCIA): Thank you. My name is Sean Lomas, I'm the policy and advocacy manager for Spinal Cord Injuries Australia.

MR KILLEEN (SCIA): Greg Killeen, Spinal Cord Injuries Australia, policy and advocacy officer, work with Sean.

MR LOMAS (SCIA): Basically. Just to introduce our organisation, obviously work for Spinal Cord Injuries Australia. We've been going for about 40-plus years. Set up by a group of individuals who had acquired spinal cord injuries in New South Wales and were looking to try and find services that would meet their needs. The organisation sort of formed around that and then started sort of lobbying effectively to try to get services up and running. One of the ones that we did manage to achieve was the attendant care program. We're currently involved in a number of actions ourselves, which is we've just presented to the Lifetime Care scheme's annual inquiry. We present on an annual basis to that. We participate as an organisation in budget estimates process within New South Wales. We are currently involved in an inquiry into age and disability and home care looking at quality service provision and how the government plans for future need. We, about a year ago, wrapped up an inquiry into aids and equipment. We are very, very committed to good, decent outcomes for people with disability, proper planning and responsive and effective government. Okay, any questions?

MS SCOTT: All right. Want to keep going or should we start with questions?

MR LOMAS (SCIA): I probably should just say that we actually - we framed our submission into 10 principles.

MS SCOTT: Yes.

MR LOMAS (SCIA): These are sort of 10 sort of - not guidelines but they're sort of 10 ways that we're looking at the whole moving forward with the scheme, was we've called it, because we're obviously quite careful that it probably won't be called a National Disability Insurance Scheme. It might be called something else. So I think a scheme is a good all-encapsulating word to frame it under.

We've touched on various different things there from compensation payments - we've tried to put a great emphasis on actually recognising that at present there are issues about how services are developed, and tried to build in a multi-layered approach to ensuring that there's effective ways of regulating those services and ensure that they're high quality for the individual.

We looked at funding, in particular looking at the New Zealand model and how that's developing or going and how that's contrasting with what could potentially happen within Australia. Looked at buy-in as well, from people that are actually accepted onto the scheme and how - what role that they should actually have in determining how the scheme operates and how supportive guidelines sort of develop over time, accountability et cetera. Yes, I think that's about it.

There's an element there about cure as well, that perhaps if there was any surplus cash left in the pot start looking towards cures or development and research into various different conditions and how those can perhaps be alleviated, whether it's - not necessarily just medical cure but also looking at social cure; that if there's a way that through the scheme it can drive greater social recognition of disability, could be a way of decreasing the effects of a disability. Using a pot of cash as well to sort of lobby other government departments for better access into the built environment, anything really that works to decrease the effects of a disability, I think, could be a decent role for the scheme. That's it, thanks.

MS SCOTT: Well, thank you.

MR WALSH: Thanks, Sean. I guess - I mean you mentioned in your introductory comments that you had been working with age and disability and home care around the - I think in terms of framework of service delivery?

MR LOMAS (SCIA):   Yes.

MR WALSH: Without pre-empting anything that may be confidential, could you give us a bit of an overview around your perspective on what service delivery should look like?

MR LOMAS (SCIA):   Probably not as it does now. I think very much there's - that the person with disability generally seems to sit at the bottom of the chain, far, far away from the policy planners that set up the programs, far away from the funders that set up the programs and fund the programs. Ultimately, what we really, really think should be the case is that a person who is receiver of the program knows the program better and more intimately than any government department could possibly do so. So how do they get their voices up?

It doesn't seem to be working properly because all - as an organisation that provides an advocacy service we're continually hearing on a day-to-day basis that, "This service has fallen down, this scheme doesn't meet my needs, it's not reactive enough, it stifles my ability to be able to live the life that I want to lead." Now, how do we deal with that? One of the ways that we're dealing with this is - and probably I didn't explain it well enough is that we've actually called for an inquiry into the operations of ADEC as a way of bringing in public statements as to how ADEC operate and where the deficiencies lie because we're in quite an interesting position in the state of New South Wales at the moment that everything is moving towards the development of Stronger Together 2, the next round of disability-specific funding to be announced.

We feel that perhaps without having an inquiry the degree of public consultation would not be thorough enough to ensure that unmet need is addressed, that service issues from people receiving services are addressed, and even issues that are happening from ADEC staff themselves in they motivated to go into the role, they want to provide decent services for people with disabilities and they're not getting the necessary support that they need from upper government. So we kind of opened up that process. I think it's kind of like a sit and see what happens.

MR WALSH: In terms of that, just going into it particularly with respect to New South Wales and changes around motor injury compensation over the last five years or so, I guess we have almost a dual system for people with spinal cord injury; those who have a motor injury accident and those who don't. Are you able to reflect - - -

MR KILLEEN (SCIA): Or those who are not compensated in other means as well.

MR WALSH: Or those who are not compensated at all. Can you reflect on the changes that Lifetime Care and Support may have been able to deliver and further changes that you would like to see in improving it further?

MR KILLEEN (SCIA): Look, there are very positive outcomes for some people who the Lifetime Care scheme is made for where those people, being a single vehicle accident, no-one else to blame, no third party compensation involved - for those people obviously there's a positive outcome; it's care for life. They've been provided with early intervention, looking at rehabilitation and structure, getting back into the community. I'm not sure about the role of back into work as part of their role, but equipment, aids supplied, personal care, getting resettled back into the community into some type of accessible accommodation. So that is a scheme that those people would have normally not received a properly funded, structured and coordinated scheme; they would be like the rest of us who are required to use the government-funded services to support them in the community. It's a good scheme, it seems to be. We've been through the Lifetime Care scheme review and heard various angles about the good and bad of the scheme from both the participants and from people involved in the running of it.

MR LOMAS (SCIA): Just adding to what Greg said - and we have been involved in the development of the Lifetime Care scheme through prior employees, one is Margaret Noonan - I think one of the concerns there, and we've had this since the start, is that it's always been the two-tier approach. We've always had the worry that there's sort of the gold card carrying patient in the spinal unit next to the poor person that has to fight their way through various different government application processes and problems around that. As part of our submission into the Lifetime Care scheme this year we did say that it would be an element of the committee to look into the expansion of the program or the actual costs involved in expanding it out so that all people that acquired a spinal cord injury could be represented within the scheme.

There's this comment that we've heard a few times within the inquiry which always seems quite interesting in that a person who receives services from the government, as said before, is at the end of the chain and there seems to be a bit of growing feeling that even though, yes, service is arriving a little bit more smoothly, that person is still at the end of the chain, still underneath their assessor and they're still underneath their case manager. They're having to respond to what their case manager tells them to do, which is still a bit worrying, and I think we put into our draft submission that we hope that through getting different levels of buy-in from the person who's the service receiver that they can actually start to develop their services themselves as opposed to being the end person having services imposed or put towards them.

MR KILLEEN (SCIA): It might be outside of the scope of this commission but I was just wondering when the actuarial stuff was being done for the Lifetime Care scheme whether they looked at what it would cost to cover people - being that it's for people who have acquired brain injury or spinal cord injury who were covered under the Lifetime Care scheme and there's been other people with severe burns and stuff - I was wondering what the cost would be to cover people who were not compensated in any other matter, in any other way, who acquired a spinal cord injury, to be covered under the Lifetime Care scheme. I'm not sure if you've done the sums on that.

MR WALSH: That's something that obviously the commission will be looking at.

MR KILLEEN (SCIA): Can I just make one slight comment. From the previous speakers you were looking at investigating stuff around the impact on people acquiring an injury and then waiting for court time. Lindsay Gething did a good study from the Sydney University a number of years ago and she interviewed maybe 200 people who had both acquired a brain injury and a spinal cord injury who were awaiting on their compensation. Changed all their names in the reports, but their perspective on what the impact was of waiting for a court case, and the outcome of that, being that the bulk of compensation is care or inability to earn a living and very little for pain and suffering, from this report some time ago there was an emphasis they would sit around and be virtually a vegetable until the case comes up because it would be perceived that you would get more money for care for life as part of the compensation.

MS SCOTT: Thank you for that. We'll follow that through. Thank you very much for the material provided and I appreciate that you've got your 10 points and I'm not trying to undervalue those, but there's just a few remarks along the way that I was wanting to focus on. For example, you talked about an arrangement where the scheme could be administered by an authority that is directly responsible to both the federal government and to its service users, talked of a membership-style approach. I haven't seen that idea before. Is that something that has operated somewhere else that you know of that we could just have a look at or is this a totally new idea?

MR LOMAS (SCIA): As far as we're aware it's a pretty new idea. It was a fairly off-the-cuff thing and it was kind of us thinking about how we'd like to participate in this. We thought what would be an ideal world solution. We recognise the practicalities of it probably will be an absolute nightmare to administer, however I think the aim is honourable, that if you can have the person that's receiving a service almost like a director or as a member, or it's run like a co-op almost, that person has buy-in. You have to set up an AGM, they can go and they could participate in that. You produce a briefing note on an annual basis so they can understand what new things have happened with the scheme, how the scheme is doing; even declare the figures, tell them how it's going financially so they can understand the bigger picture. You can hold consultations with your members and say, "We're looking at developing this. What kind of things do you think?"

It's always good to involve everybody. As I said before, I think a person with a disability receiving a service knows the service thousands of times better than the actual people who have designed the service. They know where it falls down, they know every single thing, and always they know a solution. They know the easiest ways to fix this. You'll find if you have people like that involved in the whole process you'll start getting all this new, innovative ideas coming through about how to deal with things. People aren't always going to just gripe, as it's often perceived as. They're not just going to say, "Well, it's all about money." It may well not be, it might be about service amendments. People will recognise that as well. They'll realise there's a finite pot of cash and how to work within that. I think if you empower a person with disability you get the best result.

MS SCOTT: Two more and then I'll hand back to John. In your material you indicate concern about the use of service types as community participation. It's under point 5. I'll just read it out to you. "Too often support services are pigeonholed into categories that meet the needs of the funding bodies but may be inadequate or inappropriate in supporting individual service user needs." Now, could you just talk a little bit about that, maybe examples that you know of that we might find easier to understand.

MR KILLEEN (SCIA):   I could say something. I'm assuming that the government provides funding to service providers and they need to be able to provide a certain amount of hours - more "bang for your buck" I suppose - but it may not be the type of service that the client wants. The client wants something a bit more flexible; person-centred, client-focused. So you've got this service provider, a non-government organisation, being provided with funding to provide and deliver services and the clients are saying, "Well, that's not really how I want the service to be." They're saying, "Well, we've got to report back to the government because they want us to deliver as many hours as possible. That's how we'll - so we might get allocated a certain amount of money per year for" - whether it's flexible respite, and they might want it in a certain way. They might want to get quality and not quantity and that would be one example.

MS SCOTT: Okay, good, thank you. Then my last one, I think in your introductory segment of your paper you refer to potential savings. Now, I have to say that hardly anyone ever refers to savings in submissions so I spied this one. Could you talk about the sort of savings that could be available?

MR LOMAS (SCIA):   I moved to Australia about four and a half years ago. Prior to that I lived under a Blair regime in the United Kingdom. There was a big debate that went on about the National Health Service over there and one of the solutions that the government came up with was to pour billions and billions of pounds of money into the system, which resulted in no better outcomes for patients. It ended up in an expanded bureaucracy chain and everything just sort of fell to pot. I want to comment here about the thing with cash is that we don't always necessarily agree that it's a question of throwing money at things. I think it's a question of rationalising what you've got, delivering that in a better format, making sure that that's responsive to the needs that a person has. Through individualised funding they'll buy things as they want them. Then I think you end up with potentially savings across the scheme.

There's instances that we certainly know of - many, many instances actually - where OTs and social workers are prescribing or recommending over hours for people to be supported in their own homes because they're always afraid that if they go for the actual number they need that number will never ever be met or if it falls down in some element the person will be left wanting those hours. So they over-prescribe to make sure that the person gets a level which is about right, they reckon. So there's all these extra surplus hours which are not necessarily needed on a regular basis that are being paid for and funded.

Now, if you put the onus on the person with the disability to control their hours through individualised funding they can say, "Well, this week, you know, I'm having a pretty quiet week" - I mean, I know it would be difficult with staffing and rostering and stuff like that but this is just an example. They could say, "This week I'm having a pretty quiet week. I'm going to stay at home, perhaps go out and see a movie, so I reckon I probably need about 10 hours or 11 hours this week. Then in two weeks' time I'm intending to visit a friend of mine up the coast or on this edge of Sydney. I might need a little bit of extra, more." They can start to use hours in a more reactive sense and by using that, that extra little bit that's always bolstered on top is a saving. So that's just one example, but if you start building that into other areas as well I think there is savings that can happen.

MS SCOTT: Thank you for that example, it's a good one. If you're conscious of other areas where your reforms - I mean, most people tell us the services are underfunded and that's certainly one of the themes in our issues paper but we also have been asked to try and find efficiencies and savings if it's possible, or offsets. So if you can help us in that regard that would be much appreciated.

MR LOMAS (SCIA):   Probably government reporting is always the nastiest place. It costs a lot of money.

MS SCOTT: Okay. But I think you were saying that you were involved in Senate Estimates.

MR LOMAS (SCIA):   Yes.

MS SCOTT: You have quite a transparency theme in your own text, but if you could achieve your goal of transparency and involvement but reduce the level of costs associated with government reporting that would be good. We would welcome that.

MR WALSH: I've just got one last question. You've talked a lot about the person receiving the support knows more about the service than the person giving it, which is something we've heard from a number of people. I'd like to know in that context where your organisation stands on the issue of support workers requiring certificate 3, certificate 4, et cetera, or whether the learned knowledge given by the person who is receiving the service is more important.

MR LOMAS (SCIA): I think it's always troublesome when you look at that, if you have someone that's worked in the field for a long time and knows how to do these things because they'll be used to working within the system. Then if you have to put a requirement on someone to receive education however, there is benefit in the person receiving service knowing that the person that's receiving it has some form of accredited level. I think that also extends across efficacy providers, that efficacy providers need to have some form of accreditation to ensure that people are happy with the service that they receive because they know that the person knows a little bit about what they're doing.

MS SCOTT: Greg, what about your experience? Do you personally insist that someone shows you their certificate or would you prefer to train them yourself?

MR KILLEEN (SCIA): Look, it's horses for courses. You know, it's great if someone who's about to provide - starting with an organisation that you're using, they've got some experience and they know what's required to assist you, which is great. But everyone's an individual so the thing that I need done for me would be done differently for somebody else. A lot of people like to get people who have got no experience or certificate so they can actually train them to do for them what they need rather than be trained in way that is, you know. I've heard some people say to me, "Never get a registered nurse to work for you, they're too institutionalised," because they have a set way of doing certain things, and an attitude or a way or a perception of how things are done within a hospital concept, in a hospital, opposed to working for someone in their own home to support them to do what they need to do.

I do know people who have been working in the area as personal care workers who are getting their certificate 3 and I know who just graduated with a certificate 4 and he has been working for me for 18 years. I've travelled with him a variety of places and he's very trustworthy, a big strong guy who's - - -

MR WALSH: Why did he see the need to get a certificate 4, Greg?

MR KILLEEN (SCIA): He was offered that through the employer. They said, "Would you like to do certificate 3," - and he works for two organisations and one said, "Would you like to do certificate 4?" He said, "Well, I'll take certificate 4," and he's graduated in doing certificate 4. Yes, I don't know how many people have actually taken that role but I understand that in New South Wales - I believe it's the Department of Ageing, Disability and Home Care, are seeking or asking their care workers to take on certificate 3. I think the idea is not only to give them some skills but to maybe take it on or maybe professionalise it a bit more or a better understanding about what they're doing, yes. As I said, I've got people have been working with me for a long time. There are other workers who have been working for the same period of time who have not taken on certificate 3 or certificate 4 and they're still doing a good job.

MS SCOTT: Greg, you seem to have had success in keeping people with you. Eighteen years is fantastic. We've heard a lot of people say to us, "There's this constant rotation of staff." What accounts for your success, do you think?

MR KILLEEN (SCIA): Well, I don't employ them directly, they come through Home Care, and, well, I don't know. I've seen them turn over a lot of people, you know, but I don't know - - -

MS SCOTT: I think you're being modest, but maybe in your submission you might - because genuinely we're interested in this issue because workforce is one of the areas we have to look at and we've asked lots of people about training but we've also heard a lot of people about retention rates and, as other demands come to the fore in the aged care sector, if new funding comes into this sector as a result of the government's consideration of our final report where are the extra workers going to come from? So people are thinking about this issue so I'd be interested in your thoughts on that.

MR WALSH: Could I just answer that question with a bit of a twist on it. Greg, I suspect the reason that people have worked with you for 18 years is because you're a nice bloke and good to be with. Should there be a requirement or maybe an organisation like yours provide the wherewithal for the people receiving the services to know how to work with their support workers in a friendly and cooperative way? I mean, often there's high turnover when someone is just impossible to work with.

MR LOMAS (SCIA): We're actually providing that. We're providing it for our peer support service that operates in the spinal units of New South Wales at the moment. It's a resource called Back on Track. I can make that available to you. It's a way of actually managing the people that you end up working with, better ways to be able to navigate the government system and ensuring that things work smoothly. One of the drivers for us setting up the whole thing up and having those conversations was that people weren't turning up for care appointments, people were popping in and then popping out, and then clients were sort of at the mercy of their carers saying, "Well, I don't know how to stop them." We say, "No, you know they're supposed to be here at 8.30. You can credit your time sheet, you can tick them off when they don't turn up for these things. You can tell them these are the tasks they need to do. You can schedule their task in to make sure they're all done to your satisfaction, but do it in a nice kind of way and you can work cooperatively then with your carer, but actually controlling and regulating your carer yourself is a good way to do it." So our peer support workers, as part of their talking to people newly injured with spinal injuries, are also talking to them about how to better manage services around them.

MR KILLEEN (SCIA): No, I can't really say, it's just one of those things. People come and go and some people stick around. Obviously everyone is an individual and people who acquire a disability, particularly as an adult, life turns upside for them, their family and whatever are dealing with a lot of issues. How people deal with that and the rehabilitation and transition and then the whole situation with a family with kids or a single person or professional person, someone who has been unemployed or dealing with a whole bunch of things and their perspective on life and how they then deal with the people that actually come to provide service for them - sometimes people who turn up are not trained very well, as we were talking about; may not have the experience; may be a clash of personalities; could be anything, you know. Everyone has a bad day and, you know, when someone turns up at 6.00 in the morning to assist you, you're not in a good mood - you have good days and bad days so you have to deal with that.

MS SCOTT: Sean and Greg, thank you very much.

MR KILLEEN (SCIA): I've got some questions for you.

MS SCOTT: We're coming up against the clock.

MR KILLEEN (SCIA): That's all right. Just a things I'd like to clarify with the commission. I've got involved with a number of networks and issues and things have been discussed around the Productivity Commission and the consultation phase and stuff like that about what the terms of reference are. The issue around severe and profound disability, who will the scheme support? If you've got any clarification on what that is? Will it only be for people with severe and profound disability?

MS SCOTT: Because of where we're up to in the process, we're asking that question and that's one of the key questions in our issues paper because terms of reference did say "severe and profound" but a number of people have made the point to us and a number of people presenting today have made the point to us that some people with a mild disability may have very much better outcomes in their lives with a bit of support. So when we wrote to the issues paper we talked about those in greatest need and we thought that might clarify things. But this is a key issue, who's in the scheme and who's not in the scheme, but at this stage we haven't determined an outcome.

When I was back at the office we had 85 submissions. We've probably got 100 now, so this is something we're actually thinking about and it's true to say we'll have to cost proposals and in the end we'll probably put a variety of options.

MR KILLEEN (SCIA): I know when it comes to government providing funding to support people in the community that with older people they found that providing small amounts of support, whether it's some housework and some cooking and that sort of stuff, some assistance with showering, just support in the community rather than go into a nursing home with those small amounts of funding, they look at that as well so I assume it would be similar for people with a milder disability to support them in the community might mean smaller amounts of support. Whether it would come under this scheme is another issue.

Retrospectivity of the scheme. So if and when it's up and running, does it happen to the people that support the people from that day or does it actually cover people who have already acquired and have a disability?

MS SCOTT: The way I'm reading our terms of reference is that the scheme would look at lifetime care needs of the existing population as well as the future population but I have to say we haven't had detailed discussions amongst the three commissioners working on that. That's the way I read the terms of reference but again, Greg, I reckon when you come back in May you'll be able to be respond to our draft report. You're sort of asking us questions a bit too soon.

MR KILLEEN (SCIA): They're just questions I had.

MS SCOTT: That's fine, we're happy to take them.

MR KILLEEN (SCIA): For the scheme to look at how it will work with government authorities like the Department of Housing, where you've got multiple government schemes, instead of getting a whole of government approach, you get all of them operating individually and there's clashes, like, Department of Housing where you've got an equipment program will provide the equipment like a ceiling hoist, but then you've got to get someone else to put the track up on the ceiling and then if the person leaves, the issue is that Housing wants you to make good, so there is this clash between existing government services. Like putting in an airconditioning unit, if you leave I think they're wanting you to pull it out and make good the whole - things like that.

Would the scheme look at where someone might be accessing distinct services like personal care services, would it be considering where people would just continue to access those services but they would be funded to buy into those services or they would fund the services themselves? If you've got small services that are existing that are working in a small area - like Spinal Cord Injuries Australia has some funded out-of-hours emergency nursing service which runs from 9 o'clock at night to 5.00 in the morning, seven days at week and from 11 am to 3 pm seven days a week and it's very cost-effective. If people have some crisis issues in the middle of the night and they get called out. It's only in the Randwick, Botany municipalities which is a great scheme that could be expanded further with appropriate funding. The types of assisted technology that people might receive, who will own it?

MS SCOTT: This issue has been raised with us any number of times, so it's on our radar.

MR KILLEEN (SCIA):   Who will own it and maintain and if you no longer require it any more, where will it go? A reallocation pool of equipment is something to think about. The need for an appropriate information database for data collection and management of the scheme and forward projection and budgeting and that sort of stuff. I can see some positive outcomes from the scheme being that there's a definite need to invest in disability services. It's false economy not to do so to support people to be able to be active and productive citizens.

One good thing which has been reflected in the Lifetime Care scheme is that people who are recipients of that scheme can acquire equipment, aids and appliances that are not means tested like the PADP. For people to get into employment and earn a living exclude themselves from the PADP because you require the disability support pension as the eligibility to actually access the equipment scheme. So actually having a scheme where the equipment is provided, as in Lifetime Care, those people are not means tested for their equipment so they have no issues about maintaining on a pension or working a certain amount of hours because their pension is not required to means test it against what they're actually doing for their equipment.

MS SCOTT: Can I just have your last point then, Greg, because we're running out of time.

MR KILLEEN (SCIA):   Thank you.

MS SCOTT: All right. Thank you, thanks, Sean.

MS SCOTT: The next one coming forward is Mary Lou Carter. The advertised tea break is going to have to wait a little bit, we're just running a little bit behind time but during the course of the day we'll shorten lunch and shorten the breaks, so don't worry. Now, welcome to the table, Carers Alliance. For the record would you please identify yourself?

MS CARTER (CA): My name is Mary Lou Carter. I'm the secretary of Carers Alliance.

MS BUCKWALTER (CA): I'm Maree Buckwalter, I'm the president of the Carers Alliance and also the mother of a severely disabled son.

MS CARTER (CA): And I'm the mother of a severely intellectually disabled young man as well.

MS SCOTT: Okay, thank you. Now, would you like to make a short opening statement?

MS CARTER (CA): I'd just like to say that the Productivity Commission's inquiry is very welcome. There are many thousands, tens of thousands, hundreds of thousands, of people who are awaiting the outcome of this inquiry with great hope. They've had hope for many, many decades and it would be extremely devastating should there not be transformational change that - a scheme that would not look at how the disability has occurred but look at the need, the assessment of the need. A scheme like that would - it's absolutely essential and as far as I'm concerned Australia lags by at least a generation by not having any legislation that gives rise to an entitlement for services to people with disabilities.

MS SCOTT: Thank you. Okay, are you happy to go to questions then? Thank you very much for providing additional material. Just before the meeting we had the one-pager. Could you talk about what power you see coming out of having an entitlement scheme versus what we currently have? A number of people - last week we were in Queensland and some people made the remark that there are lofty statements but finding services on the ground was very problematic. I just want to work out why you think having an entitlement will make the difference.

MS CARTER (CA): Well, the entitlement would have to be backed up by the services that would flow from the entitlement that's given by law. So therefore what we've proposed here is a scheme that would in fact provide a seismic shift, a seismic power shift, from providers of services to consumers, which is actually how Australia works. We are in a market economy. We are consumers. Goods are provided and services are provided that are innovative, flexible and that meet the needs of the consumers. So an entitlement service - an entitlement would mean that someone who can't or doesn't have the same opportunities and choices without - are backed up with entitlement and services. Those choices will be available to them if they have the entitlement. I mean we are all entitled to be able to go to work, to recreate, to follow all those things that we do in everyday life and yet people with disabilities live a sort of half life because they are not entitled to have the services that will allow them the same ordinary life that other people live.

MS BUCKWALTER (CA):   We could mention that we already have rights and entitlements to services for our disabled war veterans, and that works fine.

MR WALSH: Yes, I guess I'd like to just explore this a little bit more. I suppose the issue that's been highlighted to us on a number of occasions is what the services will look like. The notion of a market-driven industry is one that many people have desired or put forward. Very interested in your comments on the transition required to go from where we are now to where that would be. I mean the veterans example is an example. I suppose that's slightly different in the context that most of the services provided for veterans are aged care services. There are obviously some younger veterans but the majority in the aged care area. We're looking for this support scheme to be that, to be a support which is placed in the community, and it goes from cradle to grave, if you like. So just how that industry might emerge is something that we'd be interested in.

MS CARTER (CA):   Of course when you're looking at cradle to grave you're going to have those points in development - if it's a child that's born with a disability, depending on the level of disability, if there are services and interventions at the outset then the outcomes for that child would be better if that child were not given intervention at all. Many children, while we have now a very robust program for autistic children, it seems to be that autistic children are getting all the attention and those that have complex needs that don't fit into a box - there's no ticking boxes for these children and they miss out on that early intervention that would give them that head start, and they're behind the eight ball when they go to school and in every milestone that they reach from here on in.

MR WALSH: Could you talk a little bit - I mean this issue of early intervention for - I assume you're talking about children with intellectual disabilities.

MS CARTER (CA):   And physical disabilities.

MR WALSH: And physical disabilities.

MS CARTER (CA):   You know, therapies that from the outset - and they don't have to be physiotherapy or standard physiotherapy. There are other physical therapies that are not recognised here in Australia and are being used by parents, and to their great financial distress, but they believe that it's an investment in their child that is paying enormous dividends. So therefore they do that. They spend thousands of dollars a year perhaps travelling overseas or bringing these therapists to Australia to administer this therapy, to learn the therapy, because it is having such a positive benefit for their child and for the child to be learning, because of course all movement affects the brain, affects how you learn. So those things parents will do and that - there is no tax deductibility for those disability specific expenses that they entail. That is - you know, families are beggared because they want to get the services, pay for them when their child needs them, so that in the long run a dollar spent here will save, you know, 17 down the track.

MS SCOTT: Thank you for the material. It will take us some time to get through that.

MS CARTER (CA): Yes.

MS SCOTT: So maybe if we can just ask a few questions to explore points, if you don't mind. You want it to be a personal scheme, so you're comfortable with the idea of person-centred care and the individual or their parents or carers being the directors of the funding. Is that one of the concepts you support?

MS CARTER (CA): Yes.

MS SCOTT: Okay.

MS CARTER (CA): Particularly those that demonstrate a connection, a lifelong connection or a whole of life connection, those people who do see their family member with disability as being their responsibility. But it should not be an overwhelming responsibility that precludes them from being able to work and being able to undertake tertiary study.

MS SCOTT: Participate.

MS CARTER (CA): And to participate in our community. That is what is happening to families. They are becoming isolated. They aren't able to access after school care, before school care, vacation care, all those things that are freely accessible when you have a child that doesn't have a disability. The workplace participation rates bear it out. 36 per cent of mothers, and it's mostly mothers, who have a child with a disability are in the workforce while those that don't have a disability it's about 63 per cent.

MS SCOTT: And a national scheme with delivery effectively through market forces, do you see a role for state-based services in any way?

MS BUCKWALTER (CA): No.

MS SCOTT: No? Okay.

MS CARTER (CA): Not the states in the state their in at the moment.

MS SCOTT: No.

MS CARTER (CA): I see this as a national scheme. There should be standards that are - national standards, not hodgepodge of, "Oh no, it's because it's South Australia and, you know, the earth's red and it's Queensland and the rivers are wild."

MS SCOTT: Yes.

MS CARTER (CA): It just should be a national-based scheme that - - -

MS BUCKWALTER (CA): Allows people to move from state to state.

MS SCOTT: Okay.

MS BUCKWALTER (CA): And get the same services.

MS SCOTT: All right. So portability is another feature.

MS BUCKWALTER (CA): Yes.

MS SCOTT: In terms of accreditation, you have talked about the fact that sometimes people are bringing therapists here to Australia because they're not recognised. Cold you talk a little bit about that, because effectively you'd have government money passed to, say, an individual or a family. Would you be comfortable with the services not being accredited?

MS CARTER (CA): It all depends on measurable outcomes. If a child is receiving a particular therapy and that therapy is not providing the outcomes that the families want and they try another one, the outcomes have to be measurable. Anything that you're spending your money on you've got to know that in the end you're going to get the result that you want, or pretty close to it, so consumer-driven. But it has to be a measurable thing, there has got to be accountability for how that money is spent. It's not just going to be, you know, like there's a snake charmer coming over with a potion. It is demonstrated that it is working for the child. The child, if they're physically-disabled, is able to do certain things that they were not able to do.

MS SCOTT: With assessment by an outside body of that improvement or by the parents?

MS CARTER (CA): We're using taxpayer money here. Taxpayers want to know they're getting value for money, and so it would have to be an outside agency, a government agency, that does that measuring.

MR WALSH: In terms of this industry, which is a market-driven industry, I'm assuming that we're talking about the need for services. We have talked about therapy mainly so far, but to free up carers, personal care, education support, employment support, housing. Where do you see the greatest lack of an industry at the moment? So that what needs to be built up or to build itself up to the greatest extent?

MS BUCKWALTER (CA): I think in terms of accomodation services, as we have a lot of ageing parent carers. I don't know about the rest of the country, but in New South Wales we have women in their 80s still caring for 50-year-old sons. At some point in their life they should know that at the end of their days their child will be well cared for and in a place that makes them happy. We can't offer them that now. They will be caring until they die, because there isn't anything out there available to them.

MR WALSH: Do you have a view on what that supported accommodation might look like?

MS BUCKWALTER (CA): I think it needs to be flexible to the needs of the person. It's not a one size fits all. There's a lot of children out there where the only friends they make is the people with whom they live. My son wento a school called Kingsdene and there were at the time 30 children there and he made his friends amongst them. His social existence, he went out into the community, but because there were so many children in that one place he was able to make friends. He doesn't speak very well, but the proximity allowed him to make friends.

MS CARTER (CA): That's the thing with people and our focus, because we are the parents of severely intellectually-disabled young sons. People with intellectual disability oftentimes can't speak. They have to be physically-assisted to be with their friends, because they can't use social networking, they can't go on Facebook. Their need to be in the physical presence of each other is a very palpable one and it's a very powerful one, because you see the joy that they have in each other's company, and I do that on a regular basis with a neighbour whose son was a schoolmate of my son. We have this what I call planned spontaneity, and to see their unalloyed joy is really very touching.

They can't arrange those things themselves, so that is very important. Of course all of us want friendships and they nurture our spirits. Perhaps people don't think that people with disability need that friendship, but they do, and they seek friendships from people who are close to them, and that's why it's so important to have them in an environment that nurtures their own sense of self and a sense of belonging.

MS BUCKWALTER (CA): Acceptance.

MS CARTER (CA): And acceptance, absolutely.

MS SCOTT: So you don't object to the idea of a group home or some sort of bringing together of people, provided that they're willingly there, they have got the choice.

MS BUCKWALTER (CA): It should be a choice. If that person is unable to make that choice for themselves, the people that love them and have cared for them all of their lives should be enabled to make that choice for them.

MS CARTER (CA): The other thing too is that I don't believe in any forced co-tenancy, I don't believe in any prescriptive accommodation, because those are things that don't give that person that sense of, "Well, they do care about me and they do care whose company I'm in and whose home I'm sharing." The importance is the compatibility of anyone living together. If they are uncomfortable, then that has got to be taken into consideration.

Compatibility is absolutely essential when you're dealing with people who are severely intellectually-disabled, who can't make their own decisions, or very physically-disabled. It would be highly inappropriate to have someone like my son, who is a very physical, very active young man, to be placed with someone who is frail and in a wheelchair, because he has challenging behaviours and he can target that person. So those things always have to be borne in mind. Certainly I bear them in mind. Maree's son, he has been on the receiving end.

MS BUCKWALTER (CA): He is not frail, but he is in a wheelchair.

MS CARTER (CA): I just do not believe that people should be forced to live in a certain way. The general population chooses to live in whatever accommodation dynamic they like. Those choices in residence, whether it's strata units or whether it's gated communities, there's all manner of residential accommodation these days and people with disabilities should have access to those, and in fact I believe oftentimes communities can be built around people with disabilities and we don't see enough of that.

MS SCOTT: Maree, returning to your example of a woman who has a 50-year-old son and she is 85 now, in New South Wales now what is her prospects?

MS BUCKWALTER (CA): I think they're very slim in New South Wales at the moment. Basically the only way that she would actually get accommodation for her child is to relinquish him. It is that bad.

MS SCOTT: What level of respite could she realistically expect to get at the moment?

MS BUCKWALTER (CA): Possibly a weekend a month, or a day or two during the week.

MS SCOTT: Do you get a sense that the New South Wales government understands the demographic issues and is well prepared for them?

MS BUCKWALTER (CA): Not at all. I think they understand them, but they're not well prepared for them. They know what is out there. They get phone calls, they get applications, they get people saying "Help me" every day, and there's no help for them. There's no assistance, there's no respite, there's no accommodation. It's this little bit of respite and accommodation. Mary Lou was talking about compatibility. This is why we have people living in incompatible households, because they're just put where they fit, because there really isn't enough.

MS CARTER (CA): I heard Sean Lomas in his submission talk about the second tranche of the Stronger Together disability-specific program that the government has been promoting. We have come to the halfway point of that, but what is very concerning is that in this New South Wales recent budget there was not one dollar allocated to that second tranche. The excuse is that there is a pay equity claim that is to be resolved later on this year. However, it is really worrying that there are no figures in the budget forward estimates and so they don't exist, and that is very, very worrying, particularly when Stronger Together was trumpeted as the answer to disability service provision in New South Wales.

MR WALSH: Did you notice any impact of Stronger Together?

MS CARTER (CA): This is the fifth year that we're going into but there's nothing been allocated for - there are some families that are getting more respite than they've had before but it is still not addressing that future need that will hit Australia. It will be a catastrophic humanitarian crisis because parents will die and the experience that I had a couple of years ago, a lady that I had heard of, I went to visit her. She was dying of cancer. She had said to the Department of Ageing, Disability and Home Care that she was going to die and she wanted to see her son transitioned into supported accommodation in the area in which he grew up, able to access the recreation that he'd been engaged in since he was 16, for some 23 years, and be able to continue going to his day program. Well, that lady died.

I stood by her graveside with her son and her son was having hot and cold running carers because there was nowhere for him to live. It was a very, very complex issue. There were problems with the will and all the rest of it, but that young man ended up being put in accommodation that was some 60 kilometres away, it was with people he'd never met before. He lost everything. He lost his mum, he lost his house, he lost his community, he lost his recreation, he lost his day program. But he was living in the community so it would seem that any old community will do. So the sense of community, as far as I'm concerned, is used as an excuse that any old community will do. If it's a person with intellectual disability, "What would they know?" and that is just totally inhumane and unacceptable. I have tried to keep in contact with that young man because I advocated for him and I wrote letters asking to know what happened to him and I've heard nothing. So it's just an inhumane system. There has got to be change.

MS SCOTT: That's for that. Maree, going back to the example of the mother, 85, and the dependent child, 50 , do you think that mother would be able to cope with or be interested in an individualised package? Do you see the need for facilitators and intermediaries, do you see - - -

MS BUCKWALTER (CA):   She obviously has some idea of where her child would like to go and I could see her say, for instance, going to somewhere like Sunnyfield saying, "Look, I have an accommodation package. What can you offer me?"

MS SCOTT: Purchasing just like she might purchase a - - -

MS BUCKWALTER (CA):   Yes, just like going and buying a loaf of bread, you know. I mean, that's the way it would work - and if you're not happy you take your money elsewhere, which in turn, by the way, would vastly improve services because it would be market driven. I mean, because at the moment there's, "This is all there is." You know, if the service isn't good, where do you go from here?

MS SCOTT: Do you have a view about qualifications for attendant carers? We've asked a number of people this. Do you have a view?

MS BUCKWALTER (CA):   I think there should be training. In fact, I think there should be some type of course, whether it be TAFE or whether it be a university course, and I think that people who provide care should be paid appropriately. I mean, they're very poorly paid, and if we expect to have people who provide good care we should pay them appropriately and we should recognise their abilities. I mean, you have people who have worked in the industry for 10, 15 years, have vast amounts of experience. We should recognise that.

MS SCOTT: You weren't very keen on the states being the providers of care. What do you think will happen to that workforce? Does that worry you?

MS BUCKWALTER (CA): The workforce that's currently here?

MS SCOTT: Yes.

MS BUCKWALTER (CA): It would simply be employed by another boss.

MS SCOTT: And the reason why it would be better with a different boss?

MS BUCKWALTER (CA): Well, because it would be centralised throughout the whole of Australia, we would have the same services available in every state to anybody. You know, if I decided I wanted to go and live in Western Australia my son would have the same types of services, albeit in a different place, available to him when he arrived, not 12 months down the track after numerous letters and constant fighting with government bodies to get it.

MS SCOTT: Thank you. I will take your material and have a close read of it. I guess what you're basically saying is give the consumer the power and they'll work out the means to suit their circumstances.

MS BUCKWALTER (CA): I think most of them are capable of that.

MS SCOTT: All right. Thank you very much.

MS CARTER (CA): Thank you very much. Could I just say that without law - law is the only thing that will change behaviour, will mould and will change society, as is always the way, and unless we have legislative back-up nothing is going to change. Thanks for the opportunity.

MS SCOTT: Thank you very much. Thanks, Mary Lou. We're now going to have a tea break and we'd like to be back in 10 minutes, please.

MS SCOTT: Because we're on a schedule, gentlemen, I think we will actually commence and we'll just ask that people be quiet as they come back in. So thank you very much for coming along today. For the record, could you please state your name and the organisation you're representing and then would you like to make an opening statement.

MR FRANCIS (S): It's Frank Francis, Sunnyfield.

MR CLAYTON (S): Mark Clayton from Sunnyfield.

MR FRANCIS (S): After hearing the last 20 minutes of the pervious presentation I think they've pinched ours, to be honest, but I'll start anyway. On behalf of Sunnyfield I would like to thank the commission for allowing us to make our submission and to have our say on the future of disability care and support in Australia. It is fair to say that our submission is still a work in progress but there are some key points we would emphasise and I would like to start with a question for the commission: do you believe that you deserve the opportunity to have a chance at getting the best this world has to offer you?

MS SCOTT: Yes.

MR FRANCIS (S): Well, personally I believe that as well and, more importantly, as a parent I believe my 15-year-old daughter Rachel deserves that as well. Now, Rachel is healthy and she does not have a disability and I can tell you I'll move heaven and Earth to give her the opportunity to have the best life she can possibly have. In time, whether or not she takes those opportunities will be her choice. At Sunnyfield we passionately believe that people with disabilities should have the same opportunity - no more, no less, just the same opportunity as everyone else. So your issues paper elegantly proves that this is probably not the case. As I read the issues paper I went through a cycle of strong emotions.

Firstly, I was impressed. In one paper you managed to summarise all the issues, the problems and the pertinent questions we have to face up to. Then I was frustrated - frustrated by the sheer size of the task. I thought, "Is it all just too hard?" You know, do we just struggle on and do the best we can? But then I felt ashamed, you know. How could this happen in a modern and prosperous country like Australia? We should all be ashamed that a significant number of Australians are not given the same opportunity. We are letting down the most vulnerable in our society. But lastly, I was inspired. We should not lose sight of what the end game is. We shouldn't get stuck in the minutia. Remember, people with disabilities deserve the best.

We need to devise a strategy to change the world so people with disabilities can have the best life possible. Why should we do this? It's because it's the right thing to do, so we need to be brave and we need to stay focused. We need to dig in and achieve what we know is morally right for people with disabilities. We need to stay focused. The end game is that people with disabilities, we need to ensure they live their lives to the fullest. As we said in the opening to our submission, this will be achieved if we follow a person-centred approach. The quote in our submission about person-centred, it says, "It's a process of learning how a person wants to live and then describing what needs to be done and then helping that person move towards that life." There's a lot of talk about new systems and initiatives, like the National Disability Insurance Scheme on individualised funding. These are important but they are not the end game. They are only a means to an end, let's not forget that.

So what do we need to change? We need to substantially increase the funding to people with disability, this just has to happen. An insurance scheme levy like the National Disability Insurance Scheme seems to be favoured solution. Consideration should be given to additional means as well. Allocate more of the current budget to disability. For example, we should spend more on people with disability than we do on trees or submarines or whales or opera or advertising. I think you get the message.

Improved tax incentives for a family's contributions. Maybe a family with a child with a severe disability shouldn't pay any taxes.   We need to provide services using a person-centred approach which delivers what the people want and need. We have to move away from simply focusing on care for the individual. Care is vitally important, but all individuals have dreams and aspirations, we need to deliver on those as well. For person-centred to work, we need to shift the power away from the governments and the service providers to the people with disabilities and their families.

The best way to do this is to give the funding directly to them and let them decide what they want to spend the money on, when they want to spend the money and where they spend the money. Introduce flexibility into the funding arrangements. Some people may wish to remain in the current system, ie block funding, some may wish to organise the provision of their services along with their families, but most will want to be somewhere between those two extremes. It's their choice.

The service providers will have to become more efficient, effective, innovative and customer-focused; if they are not, they won't survive. This will bring the powers of demand and supply into the disability sector. The result will be that people with disabilities will get what they want from who they want when they want it. A word of caution, you should only reduce individualised funding once the level of funding has been increased for the sector, otherwise the current funding will go to fewer people than it does currently.

We need to improve the inclusion of people with disabilities in our community. Until they are valued and actually feel valued by society, we won't have full inclusion. Imagine you went through a person-centred session with your family and friends - at Sunnyfield the sort of things we look at is what is working for you, what is not working for you, we list all your dreams and aspirations and then we develop this amazing plan - but then someone says, "Here's your plan, but because of ignorance and prejudice, you can't include society or community in your life," what sort of plan would that be? Very average.

When we have full inclusion, then people with disabilities can have full lives if they want. A start for this would be including person-centred approaches into Australian legislation, just like they do in the UK. Why don't we include the UN Convention on the Rights of Persons with Disabilities into our legislation? Just imagine people with disabilities having a legal right to inclusion in our society and care provision. Finally, one thing is for sure, what we currently have is not working, the status quo is not an option. It is a whole new world and we need a whole new model to achieve what we want. Thank you for listening.

MR WALSH: Thanks, Frank and Mark. I'd like you to just talk a little bit about Sunnyfield and what it does and where you see it moving over the next five years, under the assumption that a national support scheme of some sort with enhanced funding was in place?

MR FRANCIS (S): John, I probably couldn't do that in five minutes. We have a strategy which goes over 20 years and at best we do it in an hour. But I'll try my best. Sunnyfield has been around since the early 50s. We provide services to over 1700 people right across New South Wales, right across our accommodations, our employments, day programs, respite. Sunnyfield and the sector, when we did our strategy about two years ago, was at best mediocre. We did the best we could with what we had, and a lot of things were accepted which weren't really acceptable.

The whole premise of our strategy was that just because you have a disability doesn't mean you don't deserve the best. That's why we adopted the person-centred approach and that's why we support individualised funding, because that is a catalyst to drive person-centred, right, it's not the end game. At Sunnyfield at the minute our focus is direct service delivery in those areas I've said, but in the future if you actually move the power across to the families and the people with disabilities Sunnyfield's role will probably become more a facilitator.

We might deliver certain practices, if we can do it with best practice. There's going to be a range of other services that people we support want which we can't deliver, so we'll have to facilitate it, and that can be anywhere from care right through to recreation right through to financial support management. But like I say, that takes about an hour.

MR WALSH: I was interested in your point 12 where you talk about local community networks. We have heard this from other people as well. Could you talk a little bit about how local community networks might be built up?

MR CLAYTON (S): I think, John, the issue of bringing service or meeting the needs of individuals back to the local community rather than through the very top-down, heavily bureaucratic process which is currently in place in most states, having people in the local community who understand the local service needs, who understand what the environment is like where that person lives and they can put them in contact with these people or these people or that service provider seems to me a much more practical way of doing things.

MS SCOTT: Can I just clarify something. Sometimes people say they're very keen to have person-centred funding, but it seems to be another variation of block funding. I just want to check that when you say you'd like to see the power in the hands of the individual, you'd be happy to see Sunnyfield find that it receives no direct funding, it would all come through the individual choices of people with the disabilities or their families?

MR FRANCIS (S): In a word, yes. But let me just clarify. When people talk about individualised funding, it's about choice. If you think about it, you've got managed funding, individualised funding, and, like I said in the opening, it could be from one extreme, which is block funding, a lot of families are actually happy with block funding and they're happy that the service provider does that and the take largely control; at the other end of the spectrum you have families who want to do everything themselves, and if that's the person with the disability's choice, then that's the right thing to do.

When you come forward with his new model it has got to reflect whatever people choose. One solution does not fit all. I think people get hung up a bit . I talked to some families about two weeks ago who are absolutely petrified of individualised funding, because they think they are going to lose what they have already got. I said, "No, the whole thing is it gives you the choice where you want to be on that spectrum."

MR CLAYTON (S): If I can just follow up from Frank, because Frank was giving an example. If you have a person with severe autism and the funding goes directly to an organisation like Sunnyfield to provide a day program for that person and that person has to attend a particular day program at Sunnyfield, or any other organisation, with 30 or 40 other people. That might be in complete contrast to meeting that person's needs.

Perhaps that person can't be around a large group like that, a lot of noise actually makes his day even more miserable, he becomes very anxious, challenging behaviours may increase, then the organisation is in a dilemma, "Gee, we can't keep working with a man like that, so we actually have to suspend him," right, or we might need crisis support funding now to actually give that person more support. So the structure at the moment is around providing a service which looks like that. But in fact the man probably needs a service which looks like this and it has got to be delivered over here. It's very difficult at the moment, with block funding, to be able to do that.

MS SCOTT: In your submission - I don't have the exact phrase - you talk about all sorts of forms of intervention. It's point 8. You say just because intervention didn't occur early in a life or early as a result of an injury, that doesn't mean intervention isn't still desirable or profitable. Could you talk about that for a few minutes. I guess when we see a bigger submission, if you're going to put a bigger submission in, I would be interested in any evidence you can use to support your statements there because people refer to early intervention all the time and I think you're advocating frequent intervention and I'd be interested in hearing whether you've got a different perspective from most people.

MR CLAYTON (S):   You can intervene any time in anybody's life. The example that we've given you in our submission is there are many people in the centre who have severe communication impairments. We get lost in the world of early intervention, zero to four, I think where everyone believes or many people believe that because we intervene early at years zero to four with particular kinds of therapy that a child with a severe disability will no longer become an adult with severe disability. That's just not the case. In fact that's just ludicrous. We have many people that require constant support so they may develop better communication or better understanding of the social context when they're little, but they still require probably additional supports and prompts as they get older.

The communication needs of children, adolescents and adults changes. The communication context changes. 30 years ago we didn't have electronic communication devices, now we have them. Yes, we can intervene early. Many of the issues that relate to people with severe disabilities are directly related to the fact that they can't communicate carefully or clearly and people that are supporting them don't understand what it is that they want and they can't communicate back and so you have this enormous problem. We use the example of communication because it's such an important element in decision-making and choice making in a person's life.

MR WALSH: I'd just like to change topic a little bit. You've talked a bit in your submission about the government's framework and you effectively said it has to be a national scheme with state advisory panels, "Each centre had a disability care and support program advisory panel with representations from local area communities and networks." Could you just talk a little bit about the role of the states - you clearly don't want the existing role - but how that might evolve and the various tiers of governance you see as necessary.

MR CLAYTON (S): I think the example is more that we don't see one group of people sitting in Canberra being able to direct services or direct funding to meet everyone's needs right across Australia, that there would need to be some kind of a tiered approach to how that might work and obviously the closer that you can get to the person and the family with the need, I think the better it is. So the idea of a state disability advisory group that then can work with networks perhaps in the local regions might seem a practical way of trying to work the system through. There are obviously going to be issues to do with people not getting something which they think they should be getting.

For example, if you look at the Autism Advisory scheme for the early intervention program, it's quite a good example of where they're actually giving money directly to families and they're saying to families, "You can spend money in this particular way and you need to make contact with an autism adviser in your local area and they'll put you in contact with those service providers." That's clever. A lot of mums and dads don't understand - "Who should I go to? Who should I speak to?" So some kind of a filtering system that process that information is going to make it easier for families.

MR WALSH: But in your system the money is held nationally and distributed to families directly.

MR FRANCIS (S): The New South Wales government I think has probably done the best job it can. It's just getting to the point where you need more funding and we know there are other states doing better than us - whoever does the best, let's just follow their model. I'm not bad-mouthing the New South Wales government because I think they've actually think they've done the best they can and the Stronger Together has taken us in leaps and bounds and Stronger Together 2 is going to take us to the next level. But without changing something fundamentally, it isn't going to have the big change.

MS SCOTT: Okay. May I compliment you on the clarity of your paper, we've found that very useful and thank you for attending today. We have no further questions.

MR CLAYTON (S): Thanks, Patricia. Thanks, John.

MS SCOTT: We now call Carers Victoria to come forward, please. For the record and the transcript please, can you state your names and if you would provide an opening statement, thank you.

MS BOHAN (CV): Maria Bohan and Gill Pierce from Carers Victoria. Since this initiative has been mooted, Carers Victoria and the caring families we're in touch with across Victoria are very excited and have begun to see some hope and some light at the end of the tunnel. We have been out consulting with carers this year in particular. In May we met with almost 1000 caring families. So they are very excited about the potential for this huge and needed social reform.

We have prepared a very preliminary submission. You can see it's only a few pages and we're not going to talk to all of it today. We thought we'd just talk to three key things - there are six things we want to say - but, of course, we'd love your questions and if we don't have answers to your questions we'll work on them and put them in the submission. What we wanted to do today was outline some initial views in six areas but we're only going to talk about three: a focus on families; a family-focused scheme and some ideas about principles; groups who are in need of additional support; some services needed by families. We want to comment on housing and support and also comment on individualised funding and self-management which has come up a lot. But we would like particularly to talk about families, principles and some services needed by families. Gill, families.

MS PIERCE (CV): We think that the proposed disability care and support scheme gives Australia a really good opportunity to lead the world in designing and developing a family-inclusive set of services for people with a disability. Often there are separate systems for people with disabilities and separate systems for their families which is just [dysfunctional]. We currently have two separate and exclusive kind of advocacy agendas: we have disability rights advocacy which obviously emphasises the citizenship right of people with a disability, emphasises participation and choice and it's on this that the NDIS scheme is based and the disability movement has achieved a great deal in terms of awareness of the rights of people with a disability but it tends to, in our view, dedifferentiate people with a disability and is not inclusive of them all. It gives insufficient acknowledgment, in our view, of the importance of family relationships and the common interdependence of people with a disability and their families. Rather it emphasises person-centred practice and individual choice for adults and says little about the why, when and how of family involvement and the assistance they might need.

Then parallel to that we have the carer movement which has been response to inadequate services and resources for people with a disability and their families and it's done a good job in raising carer needs for support and assistance. But it provides a really narrow definition of caring in families. Caring is seen as a functional activity. It emphasises burden and stress but says little about the person with the disability and little about reciprocity that occurs within complex family relationships. It emphasises the primary carer rather than comprehensive family needs.

We think that for many families there's a very poor fit between the policy discourse and their lived experience. Examples of that are the poor fit of notions of autonomy and independence for adults with a decision-making disability; the lack of family identification with the concept of carer which doesn't describe the rich and complex and often interdependent relationships within families and the relationship between formal and informal services and the patronising notion of carer to an adult with a physical disability.

So as a consequences of those two parallel policy discourses, we've got a confusing - and you know this, of course - and fragmented set of disability services, government structures and funding and a separate, although limited system of services and supports for families which is equally fragmented. There is no common advocacy approach between disability and carer representatives. There's competition for limited resources rather than a shared approach which emphasises common needs and a good life for people with a disability and for their families. So within this system - and I'm sure you know this too - individual families have to deal with multiple inter-agency referrals, depending on whose needs are being addressed, there are separate processes of assessment of need and needs are very commonly interrelated, poorly coordinated programs and families, in our experience, have particular difficulties, and people with a disability, at life cycle transition points.

We know that recent research is increasingly demonstrating that the shortage of appropriate services and supports for people with a disability or mental illness has negative impacts on caring families, poorer health and wellbeing, significant rates of anxiety and depression, carers frequently having disabilities and chronic illness themselves. Family carers have often limited - I think Mary Lou said something about that - opportunities for workforce or civic participation and poverty and social exclusion are features of some caring families. The government response to families focuses on respite which might be regular, planned, episodic, occasional or emergency but it's like it's working at the bottom of the cliff rather than the top of the cliff. It's focusing on families who have signs of stress or burden rather than preventing stress and burden.

We would say there will always be a need for episodic, occasional and emergency respite but you can argue that adequate accessible quality services for a person with a disability which give the person with a disability a normal rhythm of life, adequate patterns of relationship and community participation will reduce the need for respite for caring families.

MS BOHAN (CV): So you can see we're arguing for a family-focused scheme. In Australia in 2003 it was estimated that of people with a severe or a profound activity restriction, aged five to sixty-four, 97.5 per cent live in the community. Of these 84 per cent lived with family, 10 per cent lived alone and 3.2 per cent lived with unrelated persons. Only 2.5 per cent lived in cared accommodation. So the support and assistance provided to people with a disability by their families is very considerable.

A few key principles thinking about this scheme: we believe these are must principles - at the bottom of page 3 - both person-centred and family-focused; funds people with a disability with a demonstrable need for day-to-day assistance to live life; provides assistance which cannot be delivered solely through ordinary family relationships and life and combines formal and informal care. We thought we might now say a little bit more about the services needed by families. Would that be helpful?

MS SCOTT: Yes.

MS PIERCE (CV): We're assuming that there has already been a whole lot of discussion about the services needed by persons with a disability so we wanted to complement that rather than ignore it, it's just we haven't listed those key things. We thing some of the key needs are specialist, early intervention and family support programs close to the point of onset and they might aim to achieve functional gains and improve independence for the child or adult with a disability as well as building family capacity, providing critical information and addressing of issues of loss and grief, if that's necessary.

Diverse models of early intervention would be required we imagine, for example, active rehab and therapy for those experiencing critical events, early developmental intervention for children with a disability or early intervention for children with autism. There's a need for specialist youth services to help families and people with disability to plan transitions away from education services to the services needed at adult day programs, further education or employment. There's a need for in-home outreach support and intervention to preserve family functioning and to promote independence and community participation for the person with a disability, particularly for at-risk families. We would think that at-risk families might include some single-parent families who can be really disadvantaged, some families with high-intensity care situations where the demands of carer are beyond what a family would normally have to manage, families with multiple care responsibilities. There's increasing evidence that the numbers of those are increasing. We have a particular concern about ageing parents with a disability or chronic illness themselves.

Another service needed by families, services for people with a disability which ensure that their families have the option of workforce participation. I think someone mentioned outside school hours and vacation care earlier. At the moment, in Victoria anyway, there is little outside school and vacation hours care available for adolescents and almost nothing available for families of adults with a disability. There are equity issues, I guess, between what families with young children get and what families who have people with other sorts of dependency needs can get access to. This is going to become an increasingly important issue as housing unaffordability becomes an issue and parents both need to work, as some of our members have been telling us.

The final area we'll talk about is there's a need for support for families with legal planning, financial planning and succession planning for the future. We will leave it at that.

MS SCOTT: I know you want to come to housing, so we might need to leave a few minutes for that. Let's go to questions though. One of the things that people have told us is that families who have this special responsibility and special role they've accepted and taken on, they don't see it as going on forever and they would like governments to recognise that, I don't know, after 25 years of care the burden of responsibility should shift a little or a lot. You're emphasising the family nature of current arrangements. You're saying the family and the individual should remain the focus of any future scheme. Could you then comment on this idea that has been put to us a number of times that after 25 years it's really the government's responsibility in the main to work out what the right accommodation setting should be or it's the government's responsibility to ensure that there are sufficient activities for those people who have limited opportunities to be engaged in the community.

So it's like some families are able to finally tell their students at age 27 it's a good time to head away from home. What's your view on that or do you see that idea of - it won't be a set age but that idea that there has to be a shift at some point between informal, loving family settings and something else. Do you have a view on that?

MS PIERCE (CV): Yes, we would say that it would be desirable if the resources are available for families to have the option of their sons or daughters moving into independent living, supported community living or whatever. From families we know some families would choose that and are keen for that to happen, wanting to become empty-nesters, I suppose. But there are other families who are very happy for their sons and daughters to remain within the family home, it's not either/or.

MS BOHAN (CV): I think that's what we hear from families, it's not black and white.

MS PIERCE (CV): The length of caring and the right to retire, if you like, is a critical issue for those older families.

MS SCOTT: We've also heard about the rights to retire for people who are in supported activities that at the age of 70 lots of people are easing off on their workloads but because in some states there isn't alternatives it's supported activities or nothing. Would you like to comment on that?

MS BOHAN (CV): I was going to say that for many of those families, not only is it very frightening, "What happens if they get sick or die? Who is going to care for the person with a disability?" The other things is that if we were supporting those families through the decades and someone was having conversations with them about the future, about financial and legal issues, about what the person with disability wanted. It's all about the journey and it's all about being supported and having key relationships with good support for the whole journey. We have a critical issue in Australia at the moment with the number of ageing parent carers and I'm sure you are hearing that from everyone and they're not in their 70s, some of them are in their 90s and 80s.

MS SCOTT: Yes.

MS PIERCE (CV): And some of them are saying that they will abandon their sons and daughters and with enormous pain about being driven to that.

MS SCOTT: Yes, we heard some very moving testimony in Queensland on reliquishments and it's very difficult.

MS PIERCE (CV): Can I just say a little bit more about housing and then I'll say something about retirement. One of the things that's lacking in the service system is some families are in a position to provide housing options themselves, some are not and the system needs to deal with both. In Victoria - I don't know about other states - we don't have a system that helps families with the complex issues of how you set up a living arrangement for your son or daughter; how you set up the legal things involved in that; if your son or daughter is severely handicapped how you work out issues of choice about who they live with and how do you set up protections if one member of a two-person household suddenly says, "I'm not going to live here any more," and so there needs to be a system to provide good advice about that sort of stuff.

MS BOHAN (CV): Not just to parents, often there are siblings in families who want to participate in that dialogue and the conversation and planning.

MS SCOTT: Yes.

MS PIERCE (CV): The other thing about retirement of people with a disability that you asked about. In Victoria the full-time day programs will often provide a retirement program that's often about community access, it might be reduced hours or reduced days of the week. I'm not sure how universal that is across the state but there's some of those. One of the dilemmas is that the shared supported accommodation obliges people to be out of home for five days a week, the centre hours, and doesn't fit with people's choice about doing other things.

MS SCOTT: Do you know why that rule exists that you have to be - - -

MS PIERCE (CV): It's about staffing resources, I think. With the innovative aged care funding there was an attempt to provide care packages for old people who lived in CRUs and my understanding is that that worked very well but it was piloted and it ended. But it enable that group presumably to have support outside of household staff so they could stay home and do other stuff.

MR WALSH: You talk a little bit in your paper here which we have just received about recent neglecting to include family. Just thinking about the 10 or 15 per cent of people who don't live with a family and particularly children don't have a family and presume live in foster care or some other supported accommodation, do you have any ideas about how to include or build the networks that are provided by a family for those children?

MS PIERCE (CV): There is certainly the need for an advocate. One thing in the context of doing some other work that I discovered in Victoria we have a system of supported residential services which are private boarding houses that are supposed to provide a bit of support and they were used a lot for deinstitutionalisation of mental health facilities and disability facilities and the average age of people in pension-only SRSs is 58 and I don't know who is going to advocate for them. It's a role families would take if families are involved. Who's going to advocate for them in the long term? I think there is a need for someone to act as advocate and good friend and make sure that they know about and get access to services that they need. It has only partly answered the questions.

MR WALSH: I'm thinking more about children who are abandoned or who are orphans, how to build family networks for those sort of children and early intervention and life support developments.

MS BOHAN (CV): I think one the exciting things about this long-term disability care and support scheme is that hopefully it will take the lid off disability in Australia and potentially get the community talking more about these issues. So that in itself will hopefully encourage people who are not in a caring family where people have support needs to potentially become a bit more involved in support. That may be a dream but hopefully that will happen.

MR WALSH: So there's nothing out there at the moment, is what you're saying?

MS PIERCE (CV):   No. With children with disabilities, again in Victoria, if they're abandoned or orphaned, I suppose, they in effect get the same access to substitute families as - I don't know about all of them - other children who don't have disabilities until they're 18. I think there is quite a good interface between the foster care kind of system and the disability system. It's not something I know a whole lot about. One of the dilemmas though - actually that reminds me - is that those substitute unrelated families get a great deal more support than a natural family.

MS SCOTT: In terms of financial support?

MS PIERCE (CV):   Yes.

MS BOHAN (CV):   And beyond financial.

MS PIERCE (CV):   It is very painful for a family who have to give up care because they can't do it any more and haven't had support to see a substitute family get that support, so again operating at the wrong end of the system.

MS BOHAN (CV):   So it's a critical issue, if some of those families were well supported along the journey the children with disability may not be cared for by someone else.

MS SCOTT: I understand. Do you know if figures exist on the number of people whose families relinquish their care?

MS PIERCE (CV):   No, but we can ask. I think it's reduced markedly but actually I don't know. I'll check.

MS SCOTT: We would be very interested to find out. Even if you could suggest a way by email to us who to contact would be very interesting. I want to go to the issue of accommodation. I'm just conscious that you have limited time with us. You've said in your short statement here that "the need for a national disability insurance scheme to be accompanied by ongoing substantial" - it sounds like it's a complementary arrangement rather than in the arrangement. Could I get you to talk about that. The reason why I'm interested is because a number of our speakers today have talked about not all families taking this up, you've said that yourself, but if the Commonwealth and the states collectively sent you a cheque, Gill, and then you'd worked out what to do with the money, would that necessarily overcome the accommodation issue?

MS PIERCE (CV): No.

MS SCOTT: Will the market provide in this case?

MS PIERCE (CV): No. What do I want to say about that? I'm assuming that the DIG report is saying that the proposed scheme will provide the support but not the housing and I guess I'm assuming that that means access to community and public housing for some people and it's our view, from the work we've done, that in Victoria people with a disability get very poor access to the vary large investment that's happened recently through the Nation Building program for community and public housing that the access has been limited and there is no shared definition of the meaning of disability, if you like, and for community housing providers there are disincentives built in to the way housing is delivered that make it more difficult for them to house people who are totally income security reliant and provide a single-person income housing which some people want, so we're really troubled about that.

MS SCOTT: Can I ask really short, sharp questions and let's see how we go.

MS PIERCE (CV): Sorry, am I waffling?

MS SCOTT: No, I'm just conscious that you have to get to an airport and I can stay here through lunch and you can't. If it turns out we can't finish this conversation with enough clarity, could you expand on this when you get an opportunity.

MS BOHAN (CV): We have done a lot of work on housing for other reasons and we can send you some of that work.

MS SCOTT: Okay. But here we go. If Gill wanted to find a speech therapist or someone with an interesting, innovative therapy, with her additional money that's been sent directly to her or her child, she should over time be able to make the connections and so on. But that's not necessarily, I think, going to work in all housing markets and I think that's what you're saying. Therefore, what I'm asking is why isn't accommodation an essential part of the scheme whereas you're saying it's complementary or should be accompanied by. I'm interested in why you don't have it in the scheme but you have it adjacent to the scheme and then you just tell me how inadequate how the current provision is.

MS BOHAN (CV): Yes.

MS SCOTT: Obviously you think there's going to be a solution and I'm happy to know that and I take comfort from the trust you have that there'll be a solution, but what I need to know is what that solution is.

MS PIERCE (CV): I made an assumption about NDIS is saying. I think it would be better if the capital was in the scheme, but at the same time I think there's a case, like they do in Western Australia, for a set target of social and public housing to be made available to people with a disability. Is that clear enough?

MS SCOTT: That's clear because now you're saying have an NDIS and have a target and possibly have some - that's been a mystery about the arrangement. That's clear now.

MS PIERCE (CV): Do you want us to send more stuff on housing?

MS SCOTT: Most people tell us that what they want is choice and that's good to hear that. Some people will tell us that there should be strict limits on what constitutes suitable housing, so if you have a view on that, that's fine. But I guess what I want to know is how we can address one of the more pressing issues in this area which is accommodation and any thoughts you have about models that work, that you know work, how we can get private developers to be interested in this housing model, the ideas of targets for the social housing, anything on that we would be most interested in.

MS BOHAN (CV): We have done work on that and we'll send it through.

MS SCOTT: Great, thank you.

MR WALSH: That would be useful. I've just got one more question and that's around how best to support families and people with disabilities and we've heard over the last few weeks, particularly about the notion of local area coordination and local networks and almost microbusinesses that operate in areas which get to know the people very well, get to know the families very well and you can tap in to almost casual labour around the place. I've got a twofold question: one is your view on this idea of community-focus support and also the nature of the people who provide the support, do they all need to be accredited workers or is your neighbour who lives across the road okay to come and help your child to get into bed if you're not there, just how it might all work.

MS BOHAN (CV): That's a big question, John. When Gill and I sat on the plane this morning to come up I commented to Gill if a family has a trusted worker who knows them and knows their journey and knows the system, they will probably travel in a better way through the caring journey. But the families who are isolated, for a whole range of reasons, some families are so stressed and angry about life and the system because they have been supported, sometimes some families need extra support and deeper relationships to get there. Do you want to add to that?

MS PIERCE (CV):   There's a strong view among some Victorian families about the value of employing - directly or otherwise - peer-age support workers for people with disabilities who share common interests, so in terms of social participation, they can enjoy something together which makes a lot of sense. We wouldn't though, in an unqualified way, support the notion of payment of families. I think it risks commodifying care and I think, however, there are issues about how you would get resources for rural isolated families and for some culturally and linguistically diverse families and you'd probably need to think about standards and monitoring and stuff where families were employed as workers.

MS BOHAN (CV):   Again, it does work sometimes in rural areas, a family employing other people in their local community but it just depends on where it is, who lives in that community, the family's access to the community and their relationships. It's not simple.

MS SCOTT: No. We heard some quite compelling evidence in Queensland last week on this topic. Maria and Gill, I think John and I are satisfied that we've asked all the questions we'd like to. John remarked in the break that we'd like to have hours' participation and I'm sorry we've had to limit everyone to half an hour. Thank you very much for your submission and early material.

MS BOHAN (CV):   Yes, it's preliminary. We're looking forward to fleshing it out and being here has been really helpful and thank you both.

MS SCOTT: Thank you. Now, we're going to have a lunch break and we're going to come back very promptly at 1.30. Thank you.

(Luncheon adjournment)

MS SCOTT: Good afternoon, ladies and gentlemen. Welcome back to our hearings. We'll commence very shortly and I'll call to the table Ron Singh. Ron, can I suggest you might move your chair a little forward. Good afternoon, Ron.

MR SINGH: Good afternoon everyone.

MS SCOTT: Thank you very much coming along today and I understand that you've travelled from Griffith to be here. Ron, you've provided us with some written material. Thank you. I think you're speaking on your own behalf, aren't you?

MR SINGH: Yes, I am and on the people's. I'm for the people.

MS SCOTT: Good. Ron, would you like to make an opening statement and then we might ask you some questions.

MR SINGH: First of all, ladies and gentlemen, good afternoon. I want to introduce myself to everyone. My name is Ron Singh. I'm from Griffith, New South Wales, from the Riverina and I'm an interpreter speaking four languages and also I'm a suicide prevention officer in the area, volunteer, and also I'm a community representative all round Australia. I do fly around with the expense of communities, the community needs very much the knowledge I have. I'm a disabled person. I'm a visually-impaired person and because I'm on a pension I always have plenty of time for the community, not only Sikh community, Indian community or other communities, all communities. I do a lot for them in the last 25 years when I started doing it and I'm still doing it. Till I'm alive I will still do in future. The community does have a lot of faith in me and I really feel glad about it. It's nice to be here this afternoon to see you people here and also thanks (indistinct) who introduced me to the ladies and gentlemen, all the people here. Thanks very much,

MS SCOTT: Thanks, Ron. Would you like to talk about what you'd like to see in a new scheme. What you would like to see as some of the reforms.

MR SINGH: Number 1 the critical barriers I've got to talk about. Critical barriers means that how can people break these barriers who are against them, especially for the disabled person, he or a she or a child or a teenager, all ages. What I'm on about to break this critical barrier, for example, when a person is disabled he is suffering enough anyway. Secondly, when he is suffering and he wants these services, services are there but they're not working. For example, one person is ill and needs a doctor urgently, it's an emergency at night. First of all, the doctor on duty in the district doesn't attend, you ask a million questions to the disabled person and he's suffering anyway but he doesn't want to attend. Lot of rules and regulations stops the person getting treated.

If he's picked up by ambulance to go to hospital in emergency, ambulance takes him from home to hospital. When the treatment is given and he is there, he wants to go back home but the ambulance said, "Sorry, I can't take you home." A person who is suffering, he doesn't know what to do in an emergency. He mightn't have money for the taxi fare to get back home. Where's the ambulance? That's one barrier, really in emergency for anyone, especially if you're disabled. You're suffering enough with your disability but then, secondly, you're suffering when you're in the never never land, there's nobody there to help you.

You have to take it really seriously, you've got to note this. I want you to note this. Also we want to break that barrier, we should urge this New South Wales government. Ambulance men take a patient to hospital in an emergency, especially when you are from the non-English speaking background and you don't have an interpreter there straightaway, you're in emergency, ambulance takes you and you're suffering in hospital and when your treatment is finished and the doctor says, "Righto, sir" - he or she - "you go home, you're very good now and you have got a pain," and the person, "I'm here at the hospital, am I? I've got no money for the taxi fare, could you call the ambulance to take me home?" and the doctor says, "Okay," and the ambulance replies and says, "Sorry, we can't take you home because there's not a law to take you home."

Now, where is the help from the New South Wales government in that sense? No. Not only once, the community urging me where this legislation. Legislation should be in place to help people. The people vote the government in to serve the public. I want to really seriously - you take this note and this should be passed on and kept on there.

MS SCOTT: Ron, can you talk about interpreting services and what's available in the Riverina.

MR SINGH: Interpreting services especially - thanks very much asking me that questions. Interpreting, for example, Monday to Friday all the departments are open, interpreters are on the line. After hours departments are not open. A lady came to me, "Ron, could you take me to doctor" - 5 o'clock all the departments are shut and you can't have an interpreter and she can't speak English and when she urgently want to go to a doctor, could be a dentist, could be other - I said, "Okay." Every dentist can't speak Indian language or any language. Interpreter's not going to be there with the person. But we want this service, interpreting services for 24 hours for little (indistinct) and whatever may be the problem is because that's non-English speaking background - all these interpreters are on duty but they're not on the duty when they're needed.

I really personally have studied that myself. I really want the government to look into after-hours interpreting, especially on weekends, Saturday half a day you've got doctors' surgeries open, hospitals they're 24 hours, whatever may be to be interpreted. In those areas there is great need for the community because all the communities are growing in Australia very rapidly and those communities, especially when they're disabled. Now, AMDAA, Australian Multicultural Disability Advocacy Association, and first of all I really great that we've got that organisation in Australia exist, which they are very good people. AMDAA has many, many things to help the public. But they can only help what help's available. They can only help where the help is. But when you go to get their help you can say that help, but help is not there in the end; what the person need, what the disabled person needs, especially from a non-English speaking background.

MS SCOTT: Ron, would you be comfortable if we asked you a few questions relating to the material that you provided us before the meeting?

MR SINGH: Yes.

MS SCOTT: Okay. John?

MR WALSH: Yes, Ron, you said you travelled a lot. I'd be interested in just telling us how easy or difficult that is given your sight impairment and particularly the difficulties other people have from non-English speaking backgrounds in travel.

MR SINGH: How difficult it is? I do have assistance to go around Australia - well, I've been doing the last 25 years. All the communities are - you know, air fare, accommodation and other taxi services they have been providing for me and to get help from me. Well, I'm a guest speaker, many places around Australia, not only for the Indian community but other communities as well. I do attend functions and lots of other things in other organisations.

Four weeks in advance I get notice where I have to go - which I have already a roster - and where I have to go, to fly in like from - well, next week is Adelaide, then I've got Perth and Brisbane and all those places on my sheet. Those communities are paying me; because when I do travel taxis give me assistance, airlines give me great - and thanks for the airlines, they do give me great assistance to travel. Then if I have a companion, like today, the organisations around Australia do pay for my companion, the food and everything. But this is not the food, this is not the accommodation or it's not just to these things but mainly to help communities around Australia. I can sit home and eat. I can have a house to go, you know, a nice comfortable house.

But it's not that. The real thing is to help communities around Australia. To get there is my responsibility, how I get to places and how I get help to the community who assists me. 25 years is a long time and all the community know me. Every time I go there on stage or at a function, all the people come to me. I don't know everyone, everyone knows me because everyone sees me here on stage, in functions especially. I'm comfortable doing things. I do have help for mobility.

MR WALSH: Thank you.

MS SCOTT: One of the things that your paper talks about is that people with mild - classified as having mild disabilities or impairment should also be part of the scheme. Could you talk about the sort of assistance that you think someone with mild disabilities should be able to access?

MR SINGH: Two or three things I want to talk about. Now, taxi service. I'm not going to mention any companies, which I'm not supposed to. Taxi services, bus services, all public transport, any region - well, Griffith is a - countryside, as everyone knows, it's the agriculture area. Griffith is a city. It has got city status. In Griffith we don't have government transport like you do in Sydney here, every 10 minutes you can get a bus. Over there, except taxi, you can get nothing. Taxi is very expensive, as everyone knows, especially out there where I'm from. Only a few cabs where I'll - one person want to go to hospital because he doesn't need the ambulance or want to go to a doctor and want a taxi, and taxi turns up one hour or 45 minutes. When you ask the taxi company and say, "What's happening? Why are you turning up late?" "Oh," says, "sorry, sir, we've only got a few taxis here."

But I, as the government, there should be some sort of buses in that area. The area is a large area. You've got Griffith, Hanwood, Yoogali and you've got Leeton, you've got Stanbridge. You've got all those little, little suburbs around the area. There's not one government transport. What transport are they? Buses for schools, they are private buses, but they're not a government transport. But apart from that we get a taxi, too costly, especially if you're on a pension or if you're on the dole, if you're old aged pensioner, whatever. But please, please, New South Wales government should please give us couple of buses over there in that area so people can get round to doctors and hospitals and you name it, wherever they want to go, wherever they need, you know. I really - doesn't matter mild disability or other; disability is a disability, but mild disability even - you know, especially for the non-English speaking background. I'm for the public.

Now, I know humans of all ages, babies, mothers, fathers, old ladies, ladies, old aged pension, all those people who have disability - my heart goes out for the families, especially for the children. I'm sorry to say, but my heart do go out for those families. A lot of families, mothers especially and with the children, because of the biggest role - biggest part played - family, you know, those mothers and a children, I'm for them. Please, I need to say that public need government transport, in our area especially; vital. That is a barrier, but the government can break that barrier, and the community will be happy and live in peace. But at the moment they're not in peace, they're not happy, and they're the ones, public, who will vote this - any government, Labor or Liberal, whatever. I'm not pointing a particular party at all because I'm not anti-politician, but politician needs to serve the public and the public has got to get that.

MS SCOTT: Okay.

MR SINGH: Thank you.

MS SCOTT: Thank you. Well, thank you very much, Ron, for coming along today. I don't think we have any further questions, so thank you.

MR SINGH: And so finally, what I've got to say, what I'm here for - I mentioned all these things should be looked at, you know, and got services, those services should be upgraded and given comfort to the public, especially people from non-English speaking background and all the disabled people especially.

MS SCOTT: Okay, well, thank you.

MS SCOTT: All right, well, we might have our next speaker come forward, Carmelita Bongco. Are you happy to make an opening statement?

MS BONGCO: Yes.

MS SCOTT: Just make a few points and then we can ask you some questions?

MS BONGCO: Yes.

MS SCOTT: Okay.

MS BONGCO: Could I be sit, I'm - this written submission.

MS SCOTT: Yes, that's fine. Just maybe five or 10 minutes.

MS BONGCO: Yes.

MS SCOTT: And then we can ask you some questions. Maybe five minutes.

MS BONGCO: Yes.

MS SCOTT: Well, welcome, Carmelita. Would you like to indicate your full name? I think you're representing yourself, aren't you, you're not representing an organisation?

MS BONGCO: Yes, I am. Is this okay?

MS SCOTT: That's good, I think.

MS BONGCO: Good afternoon, everyone. My name is Carmelita Bongco, 69 years old, was born in the Philippines, where I was affected by polio, affecting my lower extremities up to my right hip. I was only one year old. I was fortunate to have the full support of my family, especially my mother, who encouraged me not to have self-pity and inferiority complex at a very young age. I finished my elementary, secondary and bachelors degree in the Philippines and I used to be just carried by my classmates for a while before I really had a chance of learning how to walk with crutches, when I was already in year five.

Before being sponsored by my sister to migrate to Australia, I worked continuously for 20 years in the Philippines, employed as personal assistant, senior stenographer and executive secretary up to 30 April 1986. My younger sister here in Sydney sponsored me to migrate to Australia in the 1986 revolution against the Marcos regime. It is of common knowledge that the Australian government does not approve people with any type of disability to migrate here, due to restrictions in the Migration Act. After nearly two years my travel papers were finally approved and I arrived here in Sydney on 11 May 1986. After two weeks I started working as clerical assistant in a taxation specialist office. I was employed by the Water Board for 11 years. At the age of 58 I applied for a redundancy package which was reluctantly approved in 1998.

I consider changes as challenges.   By next year I will have turned 70. In early 2007 I went to the Department of Immigration. I inquired about the possibility of getting a carer from the Philippines who will stay with me and look after me, especially when I go to the shower room and toilet, cut up the ingredients and cook this for me. This has been my difficulties, living alone. This difficulties will increase as I get older. I would like my niece to be my carer. I have known my niece, who has shown considerable patience to do this for me, even when I was still in the Philippines. I was told point blank that the Migration Act 1958 states eligible relatives as spouses. I am single; parents both already passed away; children, don't have any; brother lives in USA with his family; sister lives here in Sydney but working and looking after her sickly husband; only one surviving old aunt in the Philippines; an old, senile uncle; nieces and nephews overseas who are already married; three grandchildren who are not even five years old; grandparents who have died ages ago; half-brothers and half-sisters, I don't have. In short, I cannot get my first cousin's daughter, my niece, as my carer.

In our culture we don't distinguish between first cousins. This means there is no distinction between immediate and extended family members. This distinction in the Migration Act limits the potential pool of carers for me. In the absence of the family paid carers and support services are available here in Australia. This doesn't live up to my expectations because they simply don't understand my cultural background, lifestyle and beliefs, which I had already been used to. As to the cost in accessing these services there are a number of organisations but I have to rely on their assessment of my special needs and their quality over it is entirely different from what I would expect from my niece. The paid carers are always looking at my wall clock so they can leave my place right away. Some cannot fully understand what I am talking about, even if I talk to them in plain English.

The Migration Act 1958 should be amended as to definition of "immediate family" so that extend family members from overseas can be granted carer's visa. This is my main issue and concern for the betterment of ageing non-English speaking background people with disability like myself. There is a significant unmet need in disability services. The rest of my family have their own families or are working. How can they come to Australia to be my carer? I don't have lots of money, so it is difficult to pay for the application fees. This may not even be refunded by the Department of Immigration when they reject my application. I simply don't know what to do.

MS SCOTT: Okay, thank you very much.

MR WALSH: Thanks very much, Carmelita. I guess - it must be very difficult for you. I'm trying to understand - I mean your main issue seems to be that you don't feel that the carers available here are what you would expect from your family carers. Is there a - just thinking about perhaps a network of carers from the Philippines. Are there networks of Filipino carers in Australia?

MS BONGCO: I'm not sure about that, but I really would like my niece, who is the daughter of my first cousin, to look after me and to look after my needs, because here - she has already did that when I was still in the Philippines. I know her fully well.

MR WALSH: Is the idea that she would come here and live with you and sort of be your full-time carer?

MS BONGCO: Yes. If - that's a very big if - if the Migration Act will be amended to include extended family members instead of just immediate family members, which I don't have.

MR WALSH: You say that you're not happy with the care that's available. Have you used carers in the last - you've been in Australia 25 years. Have you used carers all that time?

MS BONGCO: Well, at first I only had this home care services. It was not even for me. It was for my mum and dad, who were still with me during those time, and then - during those time as well I was working with the Water Board. So never did I realise that later in my life I would need someone to look after me, even just for domestic assistance. Domestic assistance just means that they clean my place, they vacuum it, my bathroom, and that's just about it. They don't cook for me. But I'm finding it really hard because I live by myself. I just look at the bright side of life, I really think positively, and even if I say these difficulties will increase as I grow older, I still hoping and praying that someone really can look after my special needs in the future.

MS SCOTT: I guess your case goes further than our terms of reference. No-one else has raised the Immigration Act with us. Have you thought about what you can do if the government does not change the Immigration Act?

MS BONGCO: I really hope that there should be a change with this Migration Act. This dates back 1958 anyway. Well, the bottom line is, if I really need someone who is going to look after me I don't think I can expect it from these paid carers. I had a chance of really having one but then he was always looking at the time and was always in a hurry. He doesn't even like to wait a little bit because I'm very slow, but still, I just have to accept that for a while. But I'm looking forward to my future. Hopefully, I might still be able to do some of these things by myself, although I am really having difficulty living alone. That's how I face it, that's the reality, and hopefully the government might be able to change this to the extended family instead of immediate family members which I really don't have.

MS SCOTT: Thank you very much for bringing your case to us, Carmelita. Thank you for your time.

MS BONGCO: Thank you so much for having me as well. I'm not only speaking for myself. I reckon there are still so many living alone just like myself, and hopefully this Migration Act should be amended really.

MS SCOTT: Thank you.

MS SCOTT: Our next presenter is Korey Gunnis and Laurie Strathdee.

MS SCOTT: Good afternoon. Welcome to the inquiry. Could you please state your name and then you might like to make an opening statement.

MR GUNNIS: My name is Korey Gunnis, and Laurie Strathdee is my colleague. Thank you for having us this afternoon, Patricia and John. You asked us to introduce myself. I'm a volunteer in the Blue Mountains at the Katoomba Neighbourhood Centre. I'm on the anagement committee on that organisation and I've had a disability my whole life. I was born with cerebral palsy and I've got rheumatoid arthritis, osteoporosis, depression and anxiety. I'd just like to first of all talk about the Katoomba Neighbourhood Centre, Wentworth and the community for disability. The Katoomba Neighbourhood Centre is a community not-for-profit centre based in the upper Blue Mountains, New South Wales. In relation to providing disability services in our local community, the Katoomba Neighbourhood Centre runs projects such as the Katoomba Volunteer Home Visitors Scheme, the Blue Mountains Home Modification Service and the Vale Street Social and Recreational Services, which provides services for people with a mental illness.

Firstly, regarding the Katoomba Volunteer Visitors Scheme, it's a service which is largely supported by volunteers which provides in and out-of-home care and supports people of all ages with disabilities by providing services which enable these people to remain in their own homes. Secondly, the Blue Mountains Home Modification Service is a service that provides assistance for people living with disabilities in their homes, providing modification and maintenance such as providing assistance with widening doorways, bathroom and toilet grab rails. The Vale Street Recreational and Social Service provides services such as creative writing, poetry, computer classes, sewing, theatre sports and yoga.

As indicated in the COAG 2008 National Disability Agreement improvements were agreed to simplify funding and service delivery responsibility to make it easier to coordinate the services, close service gaps and improvement access to the right services. Indeed, this raises the question: would the objectives and outcomes of the new disability care and support scheme work in with the COAG National Disability Agreement. I'd just like to hand you over to Laurie.

MR STRATHDEE: Hello, I'm Laurie Strathdee. I'm the community development worker at the Katoomba Neighbourhood Centre. I have worked with people with disabilities for 25 to 30 years in various ways, particularly with people with intellectual disabilities and with people living with mental illness, and also people with multiple disabilities - the Spastic Centre - and a whole range of programs; social, recreational, carer. I have also worked as a project worker for regional planning, planning for services for people with disability. So I've got a range of experience and I was particularly interested to add to this commission.

I think this is a fantastic opportunity to look at the way disability services are provided. We all know there's problems. What strikes me is particularly parents and people with disabilities or their carers often talking to me about, why can't they just have the money, why can't they just have the resources for them to decide what to do with it? That just came across to me again and again, and realising that there's so many gaps in the current system. You know, there may be a recreational service for people with brain injuries but there isn't one for people with Down syndrome. There are so many you have to fit into the right box and to get the right service, and you have to go round and almost beg for the service that you need. People kept asking me, saying, "We know what we need. We know what our priorities are. If the resources were given to us we would be able to direct it into the way that we need."

So the first question is, how to improve service deliveries, coordination, cost, timeliness, innovation. That's how people would - they would have the power and the knowledge to get the services that they want. The other issue is around multiple assessment. You know, when you have a disability you have to get assessed by this service, you get assessed by that service. You're always being assessed, and you might fit that one but you don't fit that one, and it's so much time spent being assessed. The other thing was also being consulted all the time about what services they want. They get consulted, but then no services ever appear because there's no extra money to do that. So they're saying if they could have a central way of being assessed, the resources were directed to the family or the carer, the person with the disability, whoever the carer is, then they can work out how they can direct those services, what they need.

One of the questions around that as well, it's about the person's needs, their functional needs and medical needs. It's not about their diagnosis necessarily and it's not about age as well. We're currently, it seems, like the HACC services, and the federal and state governments are separating elderly services from younger disabled services. Our services, as Korey said, we have the Volunteer Home Visitors and the Home Modification Service which currently support people of all ages - elderly and younger people with disabilities who are in need. But by separating it into elderly you're duplicating services; you don't have that continuous type of service. It's around need and not around these diagnoses or age or other issues. Korey is next.

MR GUNNIS: I'd just like to address one of the questions: how to give people with disabilities or the carers more power to make their own decisions and how could they appeal against made by others that they think are wrong? We advocate an individual case management model where people living with disabilities or the carers can be assessed by an agency to identify their situation and potential needs and, if warranted, power is given to the individual to choose a particular support package.

For instance, if person was assessed as being capable of managing their own affairs an annual voucher support package could be given in which an individual could purchase required services or products in the community such as food services, carer or respite services, mobility aids, transport services.

Furthermore, a voucher system should not replace any part of the income support but should only add to the support services available to a person. However, in the case of a person who's assessed as being limited in the ability to make their own decisions because of a particular disability, a case manager could assess their needs and which the individual could be issued with vouchers for a particular purchase, particular services or products. Indeed, by issuing a vouchers package, provides some flexibility and choice in what products or services people with disabilities or carers require. As well, an appeal system should exist for consumers to agitate against particular decisions made by case management, by which decisions could be reconsidered. Scope should also be given to individuals to access vouchers on a regular basis if required.

The other question I have: how to ensure that any good aspects of current approaches are preserved and what should be done in rural and remote areas where it is harder to get services? We advocate that approaches taken by current services that are assessed as being important services in the community for people living with disabilities and their carers are not fragmented or disenfranchised in order to preserve existing local infrastructure and expertise. Indeed, possible impacts of fragmentation of services is evident in the case of the Katoomba Neighbourhood Centre project, the Blue Mountains Home Modification Service which is a vital service from the New South Wales Home and Community Care program as its future service delivery is unknown due to fragmentation of the current HACC program.

For instance, as the New South Wales State HACC Aged Care Program is being transferred to federal authority it raises the question, will services such as the Blue Mountains Home Modification Service, which caters for both the aged and people living with disabilities, continue to receive similar funding under the COAG disability-aged services split. Moreover, we advocate that local services like the Blue Mountains Home Modification Service be considered an important service to be preserved under the proposed disability support and care scheme because as holders of accumulated local knowledge, both community and technical, they are better able to support and promote independent living for people living with disabilities.

MS SCOTT: Could I ask a question about that to both of you. On the one hand, you're very keen to get individualised packages, it sounds like, that you get assessed and then someone works out that you might be eligible for a $10,000 package and you're able to use the $10,000 within small restrictions, but you're able to use the money as you see fit. So that would see people purchasing services and equipment or things they need as if they were purchasing other services like they normally do with money. But then you're also concerned about fragmentation and wanting to make sure that your service is able to continue with some confidence. You've got these conflicting objectives there.

Could you talk about that, because some people have presented to us and have said, "Look, we'd like people to get individualised packages but we don't want to risk losing any of our block funding." So could you comment on the fact that if Korey was choosing things he might end up choosing something different from what he currently gets, because he would like something better, but that might mean the service provider has to change.

MR STRATHDEE: What it makes me think of is with child care centres. There's community child care centres and private child care centres. Initially at least, when there was support for community child care centres, sort of like a minimal funding to support them to remain established so that they can have the continuity - in terms of the Home Modification Service, because it has a lot of expertise, it has been doing this for 15 years, there is sort of like a step of faith, saying, "We have the expertise so people will come to us," but also, to me, there's maybe just some money to tide them over for that initial phase to re-establish as a more service-based, commercial operation.

MS SCOTT: Laurie, how long do you think you'd have to ensure that organisations had some money tiding them over for the transition? Would it be 12 months, two years, something like that?

MR STRATHDEE: I don't know, sorry. I'd have to talk to the person who runs the Home Modification Service. I do see there that's sort of dilemma there.

MS SCOTT: Korey, if you had more choice about the services you get - money was paid directly into your account, for example - do you think you'd choose different things to the services you currently access?

MR GUNNIS: Yes, if there was more choice I would, definitely.

MS SCOTT: What other services would you be interested in that you don't get now?

MR GUNNIS: Recreational support, social support agencies, employment services potentially and carer support. I've got a carer at home and, yes, I feel like it would be good if I had some more assistance around that as well.

MS SCOTT: John?

MR WALSH: Yes. Thanks, Laurie and Korey. I'm interested in the Blue Mountains neighbourhood volunteer scheme and also the home modification scheme. What were the driving forces for setting up those organisations.

MR STRATHDEE: Katoomba is the upper Blue Mountains area. A lot of elderly people retire to the area. North Katoomba is a low socio-economic area as well, because it's cheap housing basically. It might be cold, but it is cheap. There's also historically a lot of guest houses in Katoomba, which have been turned into boarding houses, housing a lot of people living with mental illness. So there was perceived need for the volunteer support for people who are isolated. Lack of public transport is another thing. There is a train line down the middle of the mountains, but once you get off that it's hard.

People can be isolated living in their houses away from the town centre. So the volunteer home visitors go in once a week, once a fortnight, have a chat, a cup of tea, a bit of help from social isolation. There are home modification services all over New South Wales and we just happened to get the one that's for the Blue Mountains area. It may have been because that has been there for quite a while. It might be because of higher need, that we have a lot more elderly people in our community is why we got it. It may actually be to do with Katoomba Neighbourhood Centre being the first neighbourhood centre in the Blue Mountains and it got that service and has kept it.

MR WALSH: Does that operate well? The reason I'm asking these questions is in some of the hearings we have had it put forward that local community networks might be the way to organise disability services, drawing on local knowledge and local workforces and therapists, health professionals, et cetera.

MR STRATHDEE: Certainly local knowledge is important. We would certainly support that. It's getting a balance between having the local services, local organisations, that have the knowledge, have the networks. They know who is out there, know what support is available, as opposed to big organisations coming in. I must admit we do have some larger charity organisations who get the funding for a service in the Blue Mountains, but that means that one person comes in one day a week to sit in an office. They're not on the ground, they don't really know what is happening. But it's sort of like given to them for the whole area, or it might be the western suburbs of Sydney they're given, and their response to the Blue Mountains is to come in one day a week. So we feel like we're not really getting a very good service at all.

MS SCOTT: You mentioned that your work had involved working with people with mental illness. One of the issues with the proposal is that we consider eligibility arrangements. The issues paper discussed the difference between short-term mental illness and sustained mental illness and put the proposition that maybe someone with a short-term illness, for example mild depression, would not necessarily be eligible for the national insurance scheme but someone who had a condition which is more sustained or has episodic experiences should be in the scheme. Could you comment on that? What is your view on this?

MR STRATHDEE: Do you have a view?

MR GUNNIS: Yes, maybe there should be two different systems, where people with a short-term illness could access certain services that can get them through that period, whereas someone with a significant mental illness should have that longer-term support under the new scheme.

MS SCOTT: That's clear. Thank you.

MR STRATHDEE: With the short-term, a lot of that would be covered under Medicare, I would have thought.

MS SCOTT: That's right.

MR STRATHDEE: So in a sense you're saying it's a different system under Medicare, whereas the longer term isn't covered under Medicare very well, so they would certainly be included in the term "disability service program".

MS SCOTT: We probably interrupted your testimony. We have got five minutes, so do you wish to continue?

MR STRATHDEE: Yes, we'll just talk a little bit more. We're talking about rural and regional areas, and the Blue Mountains is semi-rural. In these areas if you've got a voucher or individualised package system then people can use whatever services are there, and it keeps the money in the local community and you don't have to set up a service for that community, which may be all the infrastructure costs and things like that. So it's actually a much more flexible way of providing services for rural and regional; and also, after our last couple of speakers, it also gives people from multicultural backgrounds an opportunity to have a much more flexible system to get the services from their communities that they need.

MR GUNNIS: I'd just like to quickly address that under a new scheme local infrastructure should be improved so it's more accessible for people living with disabilities. In the Blue Mountains only 13 of the 18 train stations in the Blue Mountains, inner city train lines, are not wheelchair accessible. As there is an estimated 10,000 people living with a disability in the Blue Mountains and an ageing population, these things should be addressed as well.

MS SCOTT: Korey, I just want to make sure I've got that figure right. 13 of the 18 train stations are not accessible.

MR WALSH: So five aren't.

MR STRATHDEE: That's right.

MR GUNNIS: It makes it hard to get around, for me.

MS SCOTT: Yes. It's a good figure to have. Thank you.

MR WALSH: You mentioned a voucher system. Is there any reason why you're putting forward vouchers rather than cash?

MR STRATHDEE: There was a bit of discussion about vouchers. Some people think "voucher" is a dirty word. It was in the Northern Territory, in the aboriginal intervention, it was used as a way of restricting people to only use certain supermarkets and what you could buy. To me, cash can be used for anything, it doesn't necessarily need to get used for the way that you possibly wanted. To me, it's six of one, half a dozen of the other. I think from a government point of view there is a bit more accountability with vouchers and I think the general public would appreciate the sense of more accountability if people are given vouchers.

MR WALSH: So your notion is that service providers, if you like, would need to have some sort of accreditation to receive vouchers?

MR STRATHDEE: Yes, absolutely. One of the last points we made was around the pay and conditions for workers within a lot of services, because work in the disability sector is very poorly paid, it's very undervalued. Somehow it needs to be combined as well, improve the pay and conditions for workers in the disability sector to give better quality service. As previous speakers said, they look at the clock and they're doing a job. To me, one of the things is, if workers are undervalued, how can they value the person they're looking after. It needs to be valued workers really caring, and they will care for the people. I know a lot of people in the disability sector who are very caring and really do it for the love; not for the money, I'll tell you.

MR WALSH: Just one more, Patricia. Do you have a view on whether support workers in the disability sector need to have a certificate 3 of certificate 4 or whatever is going, or is an understanding and empathy with the person with the disability more important.

MR STRATHDEE: That's two different questions.

MR WALSH: You can separate the questions.

MR STRATHDEE: Do you want to say?

MR GUNNIS: I think there needs to be some sort of accreditation, because there's so many different disabilities that a person working in the field needs to have an awareness of what they're working with to give the client the best service and to give them confidence to work with a person as well.

MR STRATHDEE: The empathy is really important as well.

MR WALSH: So they're not mutually exclusive?

MR STRATHDEE: No, you could have the accreditation without the empathy, I can tell you; I know people like that. Could I just make one more point?

MS SCOTT: Yes, just one more.

MR STRATHDEE: About financing. To me, if you're getting rid of a lot of the paperwork, the multiple assessments and things like that, you can actually provide more on-ground services for less money, or for the same money.

MS SCOTT: Laurie, how do you overcome the problem of multiple assessments? Are you going to have a central database? Are you going to have someone walk around with their - in some jurisdictions they have described it as "like a passport," able to say, "Look, if you want to know my story, want to have information about me, here it is. I'll hand it over to you, and then I don't have to go through the assessment all over again." How are you going to solve this problem of constant assessments?

MR STRATHDEE: We were told that HACC have been doing an access point demonstration model where there is a central point - - -

MR WALSH: Single point of access.

MR STRATHDEE: So a one-stop shop, great. You go there, you get an assessment, you get some paperwork, so then you can go around and shop. So it's your record. That brings in the problem of you might not like the assessment you get. So there needs to be a good appeal process, et cetera, around that. You need to have OTs and whatever therapists as part of that assessment as well. So it's not just the medical model assessment but a range of things.

The other point, about the finance is, it seems to me, by splitting the elderly from the people with disabilities, if you're talking about just disability programs, a lot of people in the community don't relate to that, people with disabilities are other people, whereas if it's one system covering age and disability it covers all of us, and so that's about the political will, for people to believe in the system, that it will cover them no matter whether they develop a disability, or when they get old they develop disabilities.

MS SCOTT: I understand that point. Thanks, Korey. Thanks, Laurie. That's good.

MR GUNNIS: Thank you for your time.

MS SCOTT: Could I have an indication from anyone on the floor if they would like to make an impromptu comment this afternoon at about 5 o'clock? Is there anyone that does want to take that chance up? No? Thank you.

MS SCOTT: We now have Margaret Anne Reynolds presenting evidence. Good afternoon. Could you identify yourself for the transcript. I understand you're representing yourself.

MS REYNOLDS: My name is Margaret Anne Reynolds. In answer to the question, why am I here, I'm here because I was a victim of catastrophic injury at work 10 years ago, and in my current life, as well as dealing with that, I'm also a full-time carer for my mother. So I have had quite an interesting experience of the aged care system as well as of the insurance base model for dealing with injury and disability.

I'm so pleased in fact that this commission inquiry is taking place, because the day I went to the hearing for my injury claim - it was not in a court because the court had been abolished, it was in a commission and it was dealt with by an arbitrator - I was so upset by the system in which I was being dealt with that I came home and looked up the conventions to which Australia was a signatory, and I found that in 2006 there weren't many of recent times. So I'm absolutely overjoyed that this issue has come up.

I must apologise, because I have limited ability to sit and stand and do concentrated work I haven't been able to prepare much in the way of written material. But I would like to address some of the questions that are raised in the issues paper at a later date, by making a submission. I was particularly interested to read pages 30 to 32, which deals with the issue of legislation and workplace injury and personal injury in relation to motor car accidents and so on.

My first thought in reading it was that I'd hate for someone reading this to be under any misapprehension that there was a workable system happening for dealing with people who are disabled, catastrophically or in any other way, through a workplace injury. In fact the system is absolutely rotten to the core, and I'm not the only person saying that. I don't want you to think I'm obsessed by this. In fact there was an inquiry by the legislative council in 2005 into personal injury in New South Wales which canvassed many more issues than I could possibly bring to your attention today.

My understanding of it, through talking to my lawyer and being in fact part of this system for seven years, has left me with what is a set of questions that I really think any kind of national disability scheme would really need to answer before they even made a step in any direction, particularly if there's any contemplation of dealing with it through an insurance model based in any way on the New South Wales state based system as currently pertains. I know nothing about other states, and it may be of course that all states are different. There may be a state that has a wonderful system, but the New South Wales one certainly isn't a wonderful system.

I think one way of understanding how the system has dealt with injured people would be to compare the numbers of people who were being given some kind of help through the system at the end of the 1990s and how many are currently being assisted post the 2001 so-called reforms to the law. My understanding is that as a result of the reforms the state government is making a profit out of disabled workers and the insurance companies are also making profits out of disabled workers, and I think this is a model which is absolutely counter to any kind of even rational understanding of how disability should be looked after.

There might be questions you wanted to ask me. Feel free to interrupt me, because I'm not reading my notes, I'm just talking and I'd be happy to stop at any point. So really I would hate anyone to think, reading that, that there was something that worked at a state level in New South Wales, from my experience.

MS SCOTT: Margaret Anne, just on that, could you, within the bounds that you feel comfortable, explain why the system didn't work for you and what we could learn from that, in terms of a disability insurance model or something like that?

MS REYNOLDS: Yes. I'm not talking any names here of course, but at the moment the insurance company has the ability to cut you off any kind of assistance at any time, for no particular reason except that that's what the decide to do.

Now, the only way you can claw your way back into the system is - well, my experience of it anyhow, because I'm only talking about that, was to see a series of doctors both on my side and their side, which over a period of 18 months amounted to six different doctors over an extended period which led to the hearing at which I was reinstated and my weekly payments were reinstituted. Now, you might think, well, how am I dealt with on a day-to-day basis? How do I get the help that I get and so on? It seems to be just really by pure luck that I'm getting any help at all. The fact that I'm getting help - I'm reliant on a person at the end of a telephone who, even though is called a case manager, apparently has no qualification to do that job except as a person who is employed to do an administrative task by an insurance company. So there's no proactive - there's nothing proactive happening there. The way they assess you is to send somebody from an OT or some sort of organisation to assess what needs you have and on that basis you're granted so much assistance for home care or whatever you need.

Well, because the system works so much on just this individual and you on the other end of the telephone, the level and the standing of the individual on the other end of the telephone in my experience has been - I don't know, there might have been seven or eight different people of extremely varying abilities, as far as I could tell, or even interest in what they were doing. So there seems to be a crying need for really the training of people in the allied health area to sort of - in disability services not so much the actual clinical questions but the daily living questions and the sort of social questions that really need to be addressed, because there has been no-one addressing my case except me.

MS SCOTT: Okay.

MR WALSH: Margaret Anne, can I just - I mean you may not want to answer some of these questions - - -

MS REYNOLDS: No.

MR WALSH: - - - but it might help us in planning the way the disability care and support scheme links with the workers compensation systems. The nature of your injury, and I guess your early - the early engagement between the doctors and your employer and WorkCover and the insurer, could you just talk a little bit about that, the two or three months immediately after your injury?

MS REYNOLDS: Well, my problem was that I - I'm in a particular position that I didn't report my injury for some time because I didn't understand that I had it and it only became obvious as a result of a completely separate issue, so there's no particular continuity. But the question you ask me about WorkCover, you would hope that WorkCover has an oversight role to play in making sure the system works. Well, in my experience there were at least two occasions where my case managers just fell apart or disappeared and weren't there and my claims for reimbursement built up and in fact just got lost in the system.

On one occasion it amounted to over $2000 and I got to the point where it's so far back that I couldn't get into the paper to sort of pick it all out again and I just gave up on it. It has happened again in between case managers. This time it was over $3000 worth of reimbursements. WorkCover had absolutely no power except to ask them would they please do something. There is no ombudsman. There is absolutely no ombudsman to ask for help, no complaints system for an insurance company dealing with workers compensation. There is nothing. I can call on nobody.

MS SCOTT: You can't go back into a court or arbitration arrangement on this? Effectively your case has been - - -

MS REYNOLDS: There is no court. There is no court and solicitors - well, one of the justifications for reforming the scheme was that the solicitors and lawyers and so on are making too much money out of it. I think it's rushed to the other extreme now where there's very little remuneration for people once they have actually got a claim through for them to do much in the way of follow up on your behalf. I think it's a rush to the other extreme.

MS SCOTT: Have you - as a result of the arbitration you're part of the scheme but you're effectively encountering all these problems: lack of continuity of case managers, poor understanding or training of the case managers, sounds like poor documentation and record-keeping by the - - -

MS REYNOLDS: Yes.

MS SCOTT: You've got effectively no mechanism to rectify the situation?

MS REYNOLDS: No, there's none. There's none except me fuming, which is really not good for my health.

MS SCOTT: Yes.

MS REYNOLDS: In fact, the period of 18 months in which I was cut off and sent through this - it was like a nightmare, actually, it was Alice in Wonderland sort of brought to - you know, to rest, really. What was I trying to say? I'm sorry - I was just talking about the nightmare.

MS SCOTT: We were just going through each of the problems that you encountered with the scheme.

MS REYNOLDS: Yes.

MS SCOTT: So what's the situation now? Have you been able to resolve any of your issues satisfactorily?

MS REYNOLDS: I've been able to resolve some of the issues satisfactorily but I think it's only because at the moment luckily I have a case manager who is a reasonable person. But I think I could have been in completely the opposite circumstance and I could be here telling you that I'd achieved - nothing had been achieved.

What I was actually trying to say was that in - it's quite clear that this model is not set up to deal with you as a disabled person. It's designed to make you sicker. It's designed, in fact really the way it works, to put you under incredible stress. Besides the fact that I was cut off for 18 months and then restored, you know, what was I meant to do in the 18 months? I was lucky because I had another income. If I hadn't another income I would have fallen into the Medicare system, into the Centrelink system, and they would have been propping up with the insurance companies were meant to be doing. As far as I understand, as soon as I turn 65 I'll be back sort of in the Centrelink-Medicare system. So it's really not a model which deals with much except, at the moment, make profits for the people who are least concerned by it, really.

I thought everything was going reasonably well as far as I was concerned but I had to go and see a doctor a few weeks ago just at the behest of the insurance company. That made me feel extremely ill in anticipation and in the doing of it, because the - I won't say what I think about some of the people I've had to deal with. But I taught in a university for 32 years. I have some idea of standards and what people could reasonably expect but the inequity of the current system is really beyond belief. So I really - because I didn't have a chance to sort of sit down and answer all the many questions that were raised by the issues paper, even though many ideas came to me, I thought, "Well, I really would like to get into that and write it down at my own leisure." What time would I have to do that? Is there any kind of a deadline for submissions?

MS SCOTT: 16 August.

MS REYNOLDS: I see.

MS SCOTT: We will take late submissions but we would prefer them before 16 August.

MS REYNOLDS: Yes.

MS SCOTT: We are then going to write a draft report which will come out in February. Then that really will be the opportunity for people to say whether we've got the ideas right. Look, we have been discussing at a number of the hearings how complaints can be handled. I have to say I think you're the first person to suggest an ombudsman to us but we have had suggested that we have public advocates or funding for advocacy arrangements. Is there - besides going off to a legal firm, which sounds like you have already done, is there any advocacy services that specialise in your type of case?

MS REYNOLDS: Not that I could see. When I investigated care - through Carelink for my mother I was sent documentation which is about this thick which covered absolutely everything that was offered in my area for miles and miles but really had no particular differentiation and description of what individual people were offering. I think it's like a maze, as far as the consumer is concerned. Really even though there are these Carelink centres they're not staffed by people who might be case managers, they're staffed again by these administrative models.

MS SCOTT: That's right.

MS REYNOLDS: I see this administrative model eating up the fees that must be paid by the government to my mother's care provided for her aged care package. In fact, the provider of the package has hardly any workers who work for them. They in fact hire the people from an agency to do the work for them. There's a huge - as far as I can see, a very large bureaucracy which this HACC money is supporting. The ratio in terms of the particular organisation at one point that was dealing with my mother, for example, was for every one worker in the field there were three people in an office. I would imagine that might be quite typical, I don't know, but I'm just reporting that from my direct experience.

MS SCOTT: We have had a number of people raise overhead costs with us and so on. Would you favour a de-centralised - I mean earlier this morning people were talking about once an assessment has been made - - -

MS REYNOLDS: Yes.

MS SCOTT: - - - of, in this case, the impact of a disability, once assessment is made that arrangement will exist where the money goes directly into the person's account, or if it's a case that they have problems with decision-making it could go into their guardian's account or their family's account and then they then organise the services, if they wish - could always go off to a third party if they want to. Is that a model that you would favour in terms of giving you greater control over what services you're after?

MS REYNOLDS: Well, yes, I would. I would favour that very much, because I do know that there are some excellent services out there. I mean I happen to live in a local council area where there is in fact the first community aid services in the state. So in fact just by pure geography my mother and I have benefited to a large extent from this local service. I would hate to think that those local services were in any way diminished. I don't know whether it's an easy task but if all these disparate groups could seek accreditation and be accredited then the best of them should survive.

MS SCOTT: Okay, thank you. John?

MR WALSH: No, thank you, Margaret Anne. I'm just thinking about your advocacy - there is a help line within WorkCover called the claims advisory and assistance service.

MS REYNOLDS: I've dealt with them a number of times, and as I said to you, some of them are quite helpful but the only thing they can actually do is to say, "Would you please do it?" "Would you send us a copy of everything you sent to the insurance company," but they have no power to tell the insurance company to do anything. So there's nothing can be done and I think this is - you know, this is just wicked. This really is wicked. The other thing that of course is really wicked from my point of view is that once you're ill and you go through this system, you are implicitly thought of as some sort of a fraudster because they send private investigators after you as well.

What is the - one can work out the psychology - someone is living solely on a WorkCover benefit, they're cut off and an insurance company sends a private investigator to see what they're doing. They've got very little access to money, so they're doing things they shouldn't be doing. They're doing things that they're actually probably damaging their health. They're filmed doing it and cut off as a result of it. At the moment I'm lucky because there's a hydrotherapy and physiotherapy facility near where I live. It's only a new one. I talk there to people who are there as a result of motor car injury and they came out of - this one particular woman came out of hospital and was given nine hours a week help and after a couple of weeks it was cut back to one hour. She said to me, "I'm carrying all my shopping bags and I think it's damaging my spine." Of course it was damaging her spine but what could she do? She was told that she was eligible for one hour a week and that was all she got.

So there is really a need for people placed in sort of - maybe I don't know, in the local area health service areas like the ACAT team who are terrifically efficient as far as I can see in terms of pointing people in the direction of what the services are for disabled people, because it makes very little difference to the person who is 64 who is catastrophically injured to the - who might be 66 and receive the same injury.

MS SCOTT: Yes, a distinction between - - -

MS REYNOLDS: There's no distinction, really, is there? No.

MS SCOTT: Well, thank you very much for coming along this afternoon and for your testimony, especially given that we drew attention to those schemes that we think about the downsides associated with them. Thank you very much.

MS REYNOLDS: Thank you.

MS SCOTT: Well, we're now going to have a break for afternoon tea, which there's just tea and coffee - but anyway there's tea and coffee and it's next door. So thank you very much. We will resume at 3.10 with Kathy Breen. Thank you.

MS SCOTT: Welcome back, ladies and gentlemen, and thank you for attending today. Kathy is now going to present to us. Kathy, for the record, could you state your name and indicate whether you're representing an individual or an organisation, please.

MS BREEN: My name is Kathy Breen. I'm representing myself, my sister and our family.

MS SCOTT: Okay, thank you.

MS BREEN: I'm also a member of the Endeavour Foundation and I understand that they will be presenting a written submission to the inquiry. So thank you for the opportunity to speak. My sister is Emma, she's Down syndrome and she's 41 years old as of last week. Emma went to two special schools here in Sydney and from the age of 18 has been in continual employment through a disability service centre. She's an excellent employee and loves work and her friends. Our mum is her primary carer and she turns 85 tomorrow. They live together and provide each other with much love, fun and support. In the last 18 months mum's health has been challenged, which meant that I have now stepped up to try and assist and work out some plans for the future along with other family members. It has not been easy, but when I look at 41 years of unpaid care that my mother has provided I know that it has to be done and we've got to start somewhere.

I found out last week that mum has never received a carer's allowance. I questioned her twice, I went through her paperwork and I still can't find it. So I'm not sure what has actually happened there, whether she's not entitled to it, but in all of that time Centrelink has never contacted her and asked whether she should be entitled or tried to address that issue. So we'll take that up with Centrelink ourselves. Our view is that there's always someone more in need, and I noted in the discussion papers that you were talking about things like some might need a little and some might need a lot. We have always thought that there's people who need a lot more, so we've just plodded along, and mum and Emma have just plodded along. So my focus is on people who are born with an intellectual inability.

I'll go through a couple of things that I've identified that I'd like to present, and then if you'd like to ask me some more questions I more than welcome that. In terms of eligibility to the scheme it's probably a very simplistic view but I see it as that a person needs to be assessed in two ways: firstly, medically by a GP or a paediatrician at birth - so we're talking intellectual disability or disabilities from birth; and then through their life functionally - so again, GPs and allied health workers looking at mobility, communication, speech, psychology and social skills, because in 41 years I can see a huge change in Emma's abilities. I'm not keen on the scales and classifying people under a particular heading but I think you have to start somewhere, and I'm sure that through these medical and allied health models that there will be a way that that can be worked out.

There's always an exception to those models, so that within that scheme there needs to be some flexibility - again, a simplistic view and you've probably heard those views before but I just wanted to restate that. I'm also concerned that within a model like that that people who are disabled are going to have to be competing against each other. I don't know how you're going to work through that, which is why I started to talk about scales, but it's already a big issue within the community: how do you differentiate between one disability when it's mild and something that's more extreme or severe, how do you allocate funding between those - and it really comes back to what is needed for the person, for the individual.

In terms of that eligibility I then see that once they're identified as, yes, being part of this NDIS scheme, that a qualified case manager is allocated to look at what their real needs are for a period of their life, or for some people for a shorter period - it might be five years. But in any case, that plan needs to be assessed or reviewed, as a minimum, annually. The plan needs to be flexible. It needs to look at the risks and take into account any changes. For Emma at the age of 41, her needs and what she will require for probably the next 15 years or longer is quite different to when she was 25. In terms of how a scheme could be financed, again quite a simplistic view, but I believe it should be added to the Medicare levy. It should become the Medicare and disability levy. The fact that this is a predictable levy, that everybody who is tax paying will contribute to, means that we're not having to compete for funding against the environment, sport, energy, all those other sectors.

It needs to be a level of funding that's committed and predictable and therefore it will probably have to be set a lot higher than we initially think. When I was trying to work out what that might be, and talking to people, people were saying, "Well, add 1 per cent to it." I'm thinking, "That sounds great," and I thought, "but I don't know why I've picked that number." It's just a nice round number. In my mind, if that was to equate to, say, $10 a week extra in tax then I think that's going to have a huge impact and improvement on the disability sector. My concern with all of this Medicare levy and disability levy is how we sell it to the general community because I think the media campaign, when or if you make that decision that that's what we're going to have, the media campaign will have to be targeted and inclusive across the community because already disabilities are seen as not a very pretty area. If people are then being asked to contribute another 1 per cent, my concern is now the disability sector will be affected from that perspective with the media.

I think the idea of means testing people for eligibility to the fund is basically mean. I think already people - and I know in my mum's case for the last 41 years and when my dad was alive they had contributed a huge amount of tax, income and financial support to looking after my sister as well as raising the rest of the family, and to have that means tested, if there was going to be this new scheme, would just put extra stress on those people that are trying to work harder to provide something better for not only themselves in retirement but for siblings and also for their disabled person.

Private health insurance, I noted in the discussion paper that there was possibility of a top-up to private health insurance as a possible option but that must ensure that it's going to be at the top level. An example of this is that Emma has just self-funded her private health insurance for the first time in her life and it's $1200 per year. That's out of her own pension, out of her own money being able to have basic - that's basic hospital and ancillary cover. My concern and our concern is what happens to her in the future if she needs more specialised care, because she won't be able to access through that basic level of cover. I understand that that premium that she paid for health cover was at the highest rate because she was 41 and had not taken that out previously, so already she's being disadvantaged.

In regards to who is the fund provider, I've heard today discussions about it being a national scheme and, yes, I think that should be right because it is the National Disability Insurance Scheme so it needs to be a federal governing body or administration. Then I've made a note here that I like the idea of portals which are where people can go - I suppose it's similar to the regional model that people have talked about today, and local models. But that portal would be able to access federal and state services as well as non-government organisations, so it's about one-stop shop, because I think within the sector people are very confused and when you've got a disability it's even more confusing.

The red tape bureaucracy must be cut and the case managers need to be suitably qualified - I know that has been raised today as well - so that they're not administrators, they are qualified to case manage people with a disability and they know the issues and the sectors. Within the funding, I see the competition for that disability sector as a big one and that needs to be minimised so that you don't have the competition between non-government organisations to get that dollar. I like the idea of it being individualised funded; however, I am concerned about how then people take that back to this non-government sector and get the best service that they can for a good price. If the competition is too high within that sector are those individuals then having to go and pay premium cost simply because that non-government organisation is wanting to charge a higher fee? So there needs to be some type of regulation between non-government organisations, the state services, the federal administration.

MS SCOTT: Could I just get you to clarify that a little bit more. Normally where there's competition, I don't know, between shops, for example, that leads to prices falling. Why would you think if there's competition - let's say your sister Emma is in receipt of a package, I don't know, a $10,000 package or something like that, which says that she can use the funds for, say, five or six different types of services, one of which might be some attendant care and some might be some planning for the future or whatever, and she can use that anywhere basically that she can obtain those services - why wouldn't it be the case that Centacare, Wesley Uniting, Endeavour Foundation wouldn't all be keen and have something on their web site which says something like, "We offer family counselling," or "We offer planning services," and you or the other people who are caring for Emma would log on, look at that and say, "Well, Wesley is offering a great package for $8000. That would leave us $2000 left over, and Centacare is offering a great package for $6500." Why wouldn't we see competition just as we see competition in the airline market or something like that? Do you think there's something different or distinctive about this type of service?

MS BREEN: Maybe I just don't know a great deal about that side of the sector. I'm just thinking in terms of the quality of that care, and I don't know if that currently happens within the sector, if Uniting can offer a better package at a higher price or whether they all have a base level that they operate at, because they're all trying to provide and cover their costs. So it's probably a bit out of my field.

MS SCOTT: I think the information we've had to hand is that most funding in most states comes through block funding. So an organisation is able to say, "We have 7000 clients. Government, give us the money for 7000 clients, thank you very much," and then, "This is what we offer." Some of the people presenting this morning are thinking very much, as far as I can tell, along the lines of the UK type of scheme where Emma and her family, you, are the purchasers and you might say, "Well, it's art class on Tuesday and a film on Thursday and on Saturday afternoon swimming down at the local pool, and it's a day centre on Monday" - you know what I mean - like, you'd work out a plan. So I just wouldn't mind you thinking a little bit more about whether you think competition would lead to better services and cheaper services for your family or whether it would lead to what you thought, which was it would lead to higher prices and a need for regulation.

MS BREEN: I think I'm probably not only talking about the cost - and again it's a field that I'm not that familiar with - but also, I suppose, what's actually offered and how accessible that is. I suppose when I came back to the case manager model - and hopefully I won't get off track here - that they would be able to source that for the individual to get, I suppose, the best package available so that you're not having to go out there and look for that shop and look for the next one and try and find it. However, if you do see that that one is offering something better, be able to come back to the case manager and say, "Look, that's going to cost an extra $1000 but I think that's going to provide a better service." So, yes, maybe I'm a little bit confused about how that all works but I am concerned that it doesn't get to that point.

MS SCOTT: Okay. We had someone present to us in Melbourne and we became so intrigued by the model I dashed away and had someone show me the forms and show me the receipts and basically show me everything. This was a case where in Victoria they had an individualised package. I think they were eligible for something like $13,000 dollars. There were five headings. One of them was Time Out and that meant Fiona got to go to the pictures every Thursday. Some time was spent with someone coming in to work with her on her calendar for the week and the fortnight and to plan all the activities and to check that she had everything in good order.

They also cooked what they described as large meals and little meals. Large meals meant that Fiona had to prepare some substantial meals that were then eaten at various stages over the fortnight, kept in her freezer in her little unit, and other times it would be about, "Well, you've got so much money. What meal do you think you'd have on that day and where do you think you'd go for that meal," or whatever. That was almost like a case manager; it was a case manager who would work with Fiona about the sort of services that she and her family wanted.

MS BREEN: I think that model is ideal. I think that it takes away some of that pressure that the family will have to deal with because in the case of our family, mum has done all of that for her or is trying to facilitate that, and is now at an age where she's finding that difficult. For us to step in - and most of us live more than an hour away or interstate - it makes it very hard to do those day-to-day things and that's my concern, I suppose, for the future. I noted a little bit earlier somebody made reference to disability and the aged being very similar and I do agree with that. Aged care assessment teams look at, I understand, some of those types of things and help people stay on track or get extra services. Maybe that's a model that you could look at in terms of replicating in the disability sector. But I think what you've described there is something that someone like Emma or other people in that age group, or even younger, could probably benefit from.

MS SCOTT: Do you mind if I tease you out again on that. You were very keen to have a medical assessment done. Sometimes people have suggested to us that if you have a doctor assess you he or she will tell you what's wrong with you, whereas if you have maybe another type of profession assess you they might tell you what you can do, what you can achieve, because they're thinking about possibilities, where your doctor is thinking about diagnosis. What do you think on that idea?

MS BREEN: I think that's where those allied health people come in really valuable because they're not just looking at what's there but what you can move beyond and how you can work within the community. So I think there's a level of the medical diagnosis that may have to happen, especially if there's people who don't fit into a category like Down syndrome - and I know of people who do have mild intellectual disabilities and yet function incredibly well, drive cars, do everything, but you can just see that they need that extra bit of help. That's where maybe an allied health-type team could provide assistance in working out what they might need in the future or currently need.

MS SCOTT: Okay, thank you - keep going.

MS BREEN: In terms of services, I've made a few notes and one is that specific services we've identified that someone like Emma would need are social networks, I'll talk a little bit more about that in a minute; access to improved transport; dental; medical, as in specialised medical; and in the future probably home or accommodation respite, which - respite isn't a service that my sister or mum currently use but I can see that that might be needed.

I think in the future in terms of medical, being able to go to a specialised doctor or a specialised health provider will be really important for her. She already has some medical issues that need to be addressed with specialist care and we have made provisions for that. Now that she has private health insurance hopefully that will be okay in the future. It still concerns me that the medical profession find it very difficult to deal with somebody with an intellectual disability. They still don't look them in the eye. They still don't ask her questions or ask if she has any questions. They usually refer to myself or somebody else for those. So there's a lot of education that needs to happen in those medical fields and allied health, but that's probably another issue altogether.

MR WALSH: Well, I'd like to just stop you there for a sec, Kathy. Very early on in your testimony you said Emma's now 41 and you've seen how she has changed, her life. I wasn't quite sure whether you meant she'd changed as in she'd developed skills or whether she'd changed as in she'd become more dependent. Could you talk about that a little bit?

MS BREEN: Probably both, John. As she's ageing it's obvious that she's becoming a little bit more self-focused, self-determined, which is a good thing, but also not wanting to engage as much in social activities. So I'm - my thoughts are that down the track if the possibility of dementia or Alzheimer's comes in then if she's not in that social networking environment or is a little bit more isolated, that could be enhanced. So there's that sort of change that's happening. But then opposing that is that probably 15 years ago she was involved in a fantastic program that was run by the Evening College, and it was a literacy course. I think she went there for probably maybe four or five years. She had to catch public transport to get there, it was on a Saturday morning. I suppose after having been at school for a number of years and then not being involved in anything like that, it brought her back to that thing of reading and writing, and she has continued with that. She is obsessed with writing and reading things and has little notes all over the place.

So that's sort of a different type of aspect of what has happened for her in say the last 15 years. That program doesn't exist any more. She doesn't have access to that. That's something that I'll talk about again in a few minutes about but there's been those changes. So there's sort of, I suppose, the mental health change but then there's - and the social impact, but then there's also that change of wanting to do new things.

MR WALSH: What I think it would be good to get a handle on is what are the critical life stages. We've heard a lot about early childhood, early intervention and - you know, in the case of Down syndrome it can start shortly after birth really - and then starting school and then starting high school and then transition to work and then ageing; and obviously different social networks and different facilitators need to kick in at each of those different points.

MS BREEN: I think in terms of early intervention, definitely. I think - she was born in 1969 and she went to two special schools up until the age of 18. I have no doubt that they assisted her. But the early intervention program at Macquarie University was not available at that stage. I only know a little bit about that and I know that people with Down syndrome have been a big part of that. I that type of a scheme or that type of intervention is a really good model that could be expanded on.

There was some discussion earlier about inclusion in general schools as opposed to a specialist school. I think she's probably gained more from being in a specialised school because of the specialised teaching. I do know early in her life the local school - one of the teachers was really keen to have her integrated into there and mum chose not to do that, and that was probably more from social reasons than anything. So I think the specialised school is a good model and I think the early intervention is really important.

MR WALSH: Thanks.

MS SCOTT: I imagine you've just got a few minutes left, Kathy.

MS BREEN: Okay, I'll try to. If I can just cross into two other areas, one is really to do with transport. She's very much reliant on public transport. She travels one and a half hours each day, so that's - sorry, each way, rather, that's three hours a day just to get to work. Her day starts at 7 o'clock in the morning when she leaves the house and she gets home at 5 pm, so that's a 10 hour day of travel and working. I can see that she's starting to get a little bit tired with that but I think that's a really important network for her to have.

Within the local government area she lives she doesn't have peer support groups. I just wanted to highlight that there is a peer support group in Holroyd area which looks at older people with an intellectual disability. They provide a pick-up service and they go to functions, social functions - as well as I think they might do some computer literacy-type things. She can't access that because it's not her local government area, okay, and she might live one or two kilometres away from that. Understandably they can only cater for so many people. There's a little model that might be worth replicating in more local areas. For her to go out on public transport at night or on weekends is a little bit difficult. Taxis are far too expensive, so she's really very much reliant on family and that little network that she has. She seems to be quite happy with that but I can see as well that she needs to have that broader interaction for her own social skills.

One other point, final point, I'd like to touch on, is education and education of workers in the sector. I think we need to be educating, and it's probably a bit broader than what the commission's requirements are but we need to be educating people within the schools about people with disabilities and promoting that the disability sector is a good sector to work in, because they're the people who are going to be coming through and caring within the sector. We need to be promoting genuine career opportunities to school students, and not just in case management but also in how to run businesses, respite care, specialised nursing, things like that. In terms of disability support workers I think they're quite underpaid.

I think that they need to have a minimum qualification, as been mentioned earlier in the day, certificate 3 or 4 or a diploma. But the other thing is - and you might want to explore this with other people as you're talking is that there needs to be some type of accreditation system for them, not just, you know, qualification. I know with the natural therapies industry you're required to be part of a registered national body like the Australian Traditional Medicine Society, so that you have a standard that you work to and you have to be doing accreditation each year in order to remain registered with that body. So something like that might help people have more confidence in the people that are working in the sector.

The other thing that I think would be great for disability workers is to have some type of tax incentive or better rates of pay in order to retain them in the sector, because even today I've heard people talking about trying to get care for themselves and not being able to retain those people. So if there's a way that that can be built into it that would be great, so that people aren't constantly burning out. Finally, criminal record checks I think are essential. I don't know if that does happen across disability services but I think there must be a criminal record check when working with people who are vulnerable. Thank you, that's all I have to say.

MS SCOTT: Thank you very much.

MS BREEN: Thank you.

MS SCOTT: Thank you. I think we asked quite a few questions along the way so thank you very much for coming along, Kathy, and to the support team.

MS SCOTT: We now ask Belinda Epstein-Frisch to come forward, please. Well, good afternoon, Belinda, and welcome to the table. Could you please state your organisation and then make an opening statement, please?

MS EPSTEIN-FRISCH (FA): I'm here on behalf of the Institute for Family Advocacy and Leadership Development, short form Family Advocacy. I've provided you already with just a few points that I wanted to talk to. I'm happy to, well, perhaps do the very briefest of summary and then you - you know, respond to your questions because perhaps then I'll address more effectively the issues and concerns.

At this point in time, really, we're aiming to put to you just some of the foundational principles that we think are really important to underpin a new scheme because we think it really does make a difference and that the Productivity Commission should be thinking about these things as the sort of criteria by which one will assess each of the parts of a scheme into the future, you know, its design, its implementation, the role that we believe that these things would provide. We're talking about a clearly identified value-based - based on the UN Convention on the Rights of People with Disability. I think that this - come support everyone, you know, this becomes motherhood statements and the Disability Services Act and what have you.

We would argue that these things are not usually taken in the serious way in which they are intended and that a system needs to be based on citizenship. The current system really people are encouraged to be dependent recipient of cares. We think even seeing people as insurance risks can move to a system where we're talking about burdens of care. We think the new opportunities from some sort of universal more entitlement-based scheme that reinforces the citizenship approach would be the way that we think you should go - that really looks at, rather than a framework that says some people can and some people can't, it's about what would it take to enable.

So that's the way in which when you're going to be thinking about eligibility and the kinds of service systems or what have you - I mean we would argue you not to be just talking about services but rather than framework of supports, because it's about, we would suggest to you, asking the right questions. Without any doubt whatever scheme will need people to help and guide people within it but a system based on case management that tends to say, "Well, this is your assessment, what services do you need," leads to a demand for more services.

We would suggest to you that a different - a framework that says what's a good life for anyone, but in this case what's a good life for a person with a disability, and then what is the role that supports may play in fostering that will lead you to a different kind of outcome; because I think that perhaps the foundational difference is that - you know, what services does a person need? Well, you need attendant care and accommodation and respite and X, Y and Z. What is a good life? All of us, when we think about that in relation to ourselves, it's about relationships, it's about people, it's about meaningful work or meaningful things to do during the day and what have you, things that make your life feel meaningful.

If we box people into services - services, I think you mentioned before, facilitative is really - rather than a case management into a service we would suggest that facilitating into opportunities and paid support, which could come from the scheme, can be a critical part of that, but, you know, the paid support is not really an end in itself. As I think you've heard from a range of people, you know, where - really believe that the opportunities should be there for people to direct their own support, that in terms of planning - in terms of funding often we hear a lot about individualised - and most jurisdictions believe they have individualised funding - but it is much more - it is allocated to services and the opportunities to really influence. It continues to be choosing from a limited menu of options et cetera.

We believe one of the options would be direct payments but there are other options that use services, absolutely, but give the person with a disability and their family or support network that control over what we would suggest the what, when, where and by whom of support so that people can really make a difference in their lives. Financial intermediaries and what have you can be a part of that. The final point is in terms of safeguards. We are talking about vulnerable people. Often in that kind of service list there isn't advocacy or other kinds of safeguards that are funded into it, but we think they will be critical and important. So I'm happy to just answer any questions or engage in discussion that you would find useful.

MR WALSH: Thanks, Belinda. The way you've described - the system that you support has been put to us before by a number of people.

MS EPSTEIN-FRISCH (FA):   Yes.

MR WALSH: I'd like you to just maybe talk a little bit about how you see us getting from where we are now to that point and what you see as the critical issues, barriers, challenges.

MS EPSTEIN-FRISCH (FA):   Okay. I think it's very important that you're engaging with the community and that the - as you go through the process of development of options and position papers and the like that that there is a lens of people with disability - you know, get to provide feedback. Transforming the system is very much more difficult. Hopefully - one of the things that will come out of it is money, that will provide a greater basis for entitlement. But systems transformation is something that I think every system has trouble with in terms of - what we tend to do is we relabel things. Once upon a time - well, just recently in New South Wales everyone had an individual service plan. Now everyone has person-centred planning but people's lives haven't changed and we've actually even lost the opportunity for discussion because we're using language so loosely.

So system transformation. I think that we need to be - somehow across the system you need to be also investing in people with disability and families to help them to actually be much more active participants in any kind of transformed system. Probably you need to be helping to create demand for that, and that might seem kind of odd but people my generation - of families have been taught to be dependent service users and it takes quite a paradigm shift to move into a world where one takes up the authority, the natural authority that one has, to direct one's own support.

So I think some of the things are about capacity building for people, it's about - perhaps in different systems, state jurisdictions and what have you, developing particular - identifying it, calling it by name, that we need to - this is transforming care, not just taking on new names. There needs to be training for services. There needs to be mentoring and support. One attends a one-off workshop and might be excited but one goes back to one's workplace and the stresses and strains of everyday life and very quickly one is back into one's old forms of behaviour and supports. So it's mentoring and changing. I think we - you know, changing, change behaviour. We need to be talking to people who are - and I'm probably not at all - an expert on systems change because that's what we need. We need a systems transformation. We've got a new opportunity and we need to capitalise on it however we can.

MS SCOTT: Belinda, the changes that you're after, this paradigm shift that you're after, what would be somewhere else in the last 20 years that you can say, "Right, that's the sort of change that I'm talking about," that sort of transformation of something.

MS EPSTEIN-FRISCH (FA):   I think the UK. We in New South Wales look with longing eyes to the opportunities available to people with disability and their families in the UK. But even in Victoria, down the road, there has been such foundational change, as I'm sure you know, pulling the silos together into one kind of eligibility process, and then people of course have the opportunity to stay in the existing service or change services. That's monumental already. Having the money with the financial intermediaries so that people get that opportunity to choose what, when, where and how they use it, and the opportunity for direct payment. So I think they're two examples that we talk about in New South Wales that aren't so difficult - they're happening - from where we could get some direction.

MR WALSH: We have heard a bit today about the role of family in the support system, and at the moment family plays an enormous part, without any acknowledgment or payment for the large part. What is your view on the role family might play in a more self-directed or individualised funding type system?

MS EPSTEIN-FRISCH (FA): I think that families often haven't been acknowledged. I think we need to give the message around that when there's a family member with a disability you can't do it alone, we help families, and that's particularly with people with disability that impacts on their capacity to make decisions. But anyone with a disability in their family or a person on their own, it's about helping to draw in other people who can assist in caring about and not necessarily caring for the person.

Most of us, for example, have got our first jobs, et cetera, through our networks. It's somebody who knew somebody, you know, to get into the job at the newsagency, or whatever it was. People with disability, unfortunately, because of their life experiences, tend to have fewer connections. So it's about helping to build those connections for a person with a disability, to help kind of embed them in family and community. I would suggest to you that families continue to have a critical role, but not all families will want to take that on and not all families will be able to take that on.

It's about having systemic supports that support the person with a disability in the family to take the level of responsibility and authority that they want, so that they will continue to be involved in deciding what support, when it's going to be, how it's going to be provided. So that it's very individualised, but there could be other people who do the leg work and actually help to make that happen. I think the difference between that and the traditional case management is that with the kind of support planning I'm talking about the person who is undertaking that is responsible and accountable to the person with disability in their family; the traditional case manager is responsible and accountable to the system.

I think that's they key. It's standing beside, enabling and supporting people to take whatever authority and responsibility that they want. That would enable everybody to have self-directed support, because it would be a whatever it takes; you know, some people would be ready to go at the bit immediately on their own, and other people will need quite a lot of help, but they might be very clear about, "I want this kind of work," "I want to have that kind of holiday," et cetera, and somebody can help them implement their dream.

MS SCOTT: I wanted to ask a question about that, because what is the good life. Your idea of a good life and John's idea of a good life and my idea of a good life might vary. So in this scheme that is using taxpayers' money, one way or another, who gets to decide what is the good life? Who gets to decide about that idea of a holiday, that the holiday to Queensland was reasonable, the holiday to Vanuatu wasn't, the holiday to New York was out of the question. Who gets to decide what is - - -

MS EPSTEIN-FRISCH (FA): In the UK you have a budget up front. All of us we could all dream, but if I've only got $2000, I'm not going - - -

MS SCOTT: I'm not going to let you off the hook that easy, because someone has got to decide what budget you get.

MS EPSTEIN-FRISCH (FA): Okay, well, you know, there's eligibility criteria that Family Advocacy at this stage doesn't want to comment on and I'm not authorised. Over time, as you put out your position more clearly, we'll certainly engage, but I don't want to do that at this stage. But we do believe there will be a fence around it, there needs to be, because resources are limited and we need to ensure that there is sufficient money for people who need significant lifetime support; just as we have argued in education, in terms of support for kids.

You know, you pass a hurdle and then it's open for discussion. We think it needs to be simple. Absolutely, families and people with disabilities need to be accountable, but all the research on the self-directed indicates that quite clearly they are even more kind of mindful of what the budget means then some services are. So that you'd put up a plan, there would be some sort of approval process. But in the UK, I understand, so long as it's not illegal, you know, there are some very broad kinds of criteria.

MR WALSH: I wanted to talk a little bit more about these linkages and support networks that you've talked about. We have heard a range of views on congregate accommodation and employment and effectively communities of people with disabilities, or people with light disabilities. What is your view on that sort of arrangement?

MS EPSTEIN-FRISCH (FA): We believe everyone needs to have the opportunity to be included in the community as an individual, but it's not about forcing people. I think that any new scheme will provide for a range of options. We would imagine when people get the opportunity to really see what it means to direct your own support and build a different kind of lifestyle, then so long as the opportunities are portable then people will walk with their money and say, "Gee whiz, I hadn't thought about that kind of thing," and we would imagine over time those kind of more self-directed individualised options would grow. But at the outset you need to have something that meets people's needs, that people want to be a part of, that builds confidence in the community. I imagine you will be providing a range of options.

MR WALSH: What are the hot topics, areas most in need right now?

MS EPSTEIN-FRISCH (FA): Opportunities for men and women with disability to move out of the family home without there having to be crisis. The way our system operates across Australia, particularly here in New South Wales, there's a certain profile around a person with a disability, and I'm talking about here people with intellectual disability of moderate to high support needs, et cetera. But the other component of eligibility is more or less family breakdown, and that's demeaning and costly, financially as well as in terms of emotional costs to all parties.

So we think a proactive system that enables men and women - not children - with disability to move out of the family home at the same time as men and women without disability, mid-20s, and government support could assist families. Family Advocacy actually have a campaign going at the moment around a supported living fund, where what we're suggesting to government is that they should be supporting the initiative of families who are planning putting in place informal support. With evidence of that, then they should be eligible for some government funding.

We're at this stage pegging it at the high-need pool attendant care kind of level, anticipating it would be used by people with disability living with people without a disability who might provide some of that, just in case, and ordinary lifestyle sort of support, with paid support going in, and that seems to be getting some resonance with government here in New South Wales with both political parties.

We're suggesting that it actually should start small, 50 to 100 people in the first year with some action research around it so we can learn as it grows. But we believe that that is a - that's a hot spot, that providing that kind of support in a timely way while families still have the capacity to contribute their sons and daughters represents hope for families.

MS SCOTT: Belinda, in your testimony you referred once to state services. I just want to check how you saw the model working. Are you envisaging a national scheme?

MS EPSTEIN-FRISCH (FA): Absolutely, it's just that the service provision happens through states. It has to be a national scheme.

MS SCOTT: And national standards, national assessment?

MS EPSTEIN-FRISCH (FA): Yes. When you say national assessment I'm not sure what you mean then.

MS SCOTT: Well, assessment on the same - - -

MS EPSTEIN-FRISCH (FA): Standardised assessment across the country, yes.

MS SCOTT: Standard assessment across the country?

MS EPSTEIN-FRISCH (FA): Indeed.

MS SCOTT: You've indicated your support for individualised packages but also accepted that other people might not want to do that. Services, do you see those states that have service provision do you see them staying in service provision? Is that something you'd welcome or not have an interest in?

MS EPSTEIN-FRISCH (FA): I think state government is, you know, outsourcing service provision wherever it can to the non-government sector. I think that there will continue to be a non-government sector. I imagine under a national disability insurance scheme we'd also see a strengthening of the private for-profit sector.

[A] few years ago I would have said - I was against money going to - government money going to private for-profit services, that you lose safeguards and why would you want profit going into - well, [I know of a young person] who has a very significant physical disability, uses attendant care support, [and their] funds were able to be used for either a private for-profit company or a non-government agency. It was most interesting because for the non government agencies – [this person was] a client. [This was] a young [person who] wanted to go to bed at 11 o'clock and really not earlier, thank you so much, but [they] needed, for work, to get up at 6.30 in the morning et cetera. The private for-profit agencies treated [them] as a customer and, "Well, yes, that's what you want, we might have a little difficulty but we're absolutely going to try and do that." The non-govs were, "Look, I'm sorry, that's not possible. We need to have a minimum start or" - you know, et cetera, et cetera in ways that were difficult.

I mean to continue the story [this person] actually went for a private for-profit agency where they were happy for [this person] to recruit [their] own staff and have them employed by [this person], which is what [the person] wanted, because that way they were people with whom [the person] felt comfortable. But after a while [this person would] provide the staff and then they weren't available [] because [this person] found good young women and they'd use them for other people and they weren't available. So [this person] did have the opportunity to move in - to use a financial intermediary and that has led to stability and having the support in the way in which [this person] wants it. So I think that it will open up competition and hopefully people will be able to get the kind of - more likely to get some of the assistance that they want in the way they want.

MS SCOTT: Thanks for that. It's very good - it's a good example. It's good to have on the transcript. A national scheme - we've got states with very, very different models and very different levels of expenditure.

MS EPSTEIN-FRISCH (FA): Yes.

MS SCOTT: And very different shortcomings and strengths. So I don't know if you're familiar with the DIG report, whether you're endorsing that proposal or you want us to harmonise to Queensland or harmonise to New South Wales.

MS EPSTEIN-FRISCH (FA): The problem with harmonisation - we've just harmonised our taxi transport things and it's kind of like a race to the bottom, lowest common denominator. That would fill me with greatest fear. I'd say harmonise at the top. I think we need to have the ingredients right, they need to be available nationally. I think some of the difficulties that some states' experience is a result of chronic under-funding over many years that have come from different political persuasions. Let's give the opportunity for them to catch up and not have a race to the bottom.

MS SCOTT: Okay. Well look, thank you very much for your testimony this afternoon. Thank you for coming along.

MS EPSTEIN-FRISCH (FA): Thank you for the opportunity.

MS SCOTT: Well, we now invite to the table Sam Lo Ricco, please. Sam, could you give your full name and the organisation you represent please, for the transcript?

MR LO RICCO (ABINSW): My name is Sam Lo Ricco and I represent Autism Behavioural Intervention New South Wales.

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

MR LO RICCO (ABINSW): Yes, I would. I can't probably - I don't want to talk too much about ABI without, various reasons, giving a little bit of a story of how we got here. I'm a single father of two children, one who happens to have a disability. James is now nine and he suffers from autism. James is actually quite lucky because James has had every service under the sun. He has been able to have those services because with the support of family, both financially and practically, I've done everything private. I haven't done anything government. So he is very lucky.

He has done an intensive ABA therapy. I don't know if you have come across that yet but it's a curricula out of the United States which is a very intensive autism-specific service which pretty much focuses on providing a child up to 30 hours, 40 hours of intervention a week. He did that for about four years. He is now lucky and also it's interesting that school has already been mentioned today. He now is lucky. He attends Macquarie University Special Education School which is by far the most fantastic school in New South Wales, if not Australia, I suspect, but I can't say whether that's true or not. But again MUSEC is expensive, it's a private school, and it requires me to make contributions of $15,000 a year. I have probably spent every cent I've earned in the last few years and probably spent $300,000 of my time. So I'm extraordinarily lucky. It's probably a real question mark as to why anyone would spend that amount of money but anyway, I did, and they're the things that you do for your children.

Where does ABI come in then? I was actually quite disappointed at myself that I was throwing so much money at my child when so many children were going without. While I was getting this - what I thought as a fantastic service, ABA was not available through government organisations. It was not funded by the government at all. So we set up ABI and developed a program to make ABA more accessible to anybody in New South Wales who wanted to access it. Yes?

MS SCOTT: Sorry to interrupt your flow.

MR LO RICCO (ABINSW): No, that's - - -

MS SCOTT: I understood at one stage that there were eight Commonwealth autism programs. So is ABA not recognised by those?

MR LO RICCO (ABINSW): No, it is. At the time - so ABI was set up four years ago and we are primarily funded by the New South Wales government. They're the ones that invested in us.

MS SCOTT: Okay.

MR LO RICCO (ABINSW): It is true that under the federal government's Helping Children with Autism package which has been in place for the last two years ABA is effectively now funded. But ABA currently is largely funded by way of a subsidy for private service providers who continue to charge clients 30-plus thousand, $40,000 a year or even $60,000 a year and the government's contribution of 6000 subsidises that service.

MS SCOTT: Can I just check on this. Is it the - is there no government provision of this type of therapy, full stop?

MR LO RICCO (ABINSW): No, it is available. State government provide it through us and they provide it through the Helping Children with Autism package.

MS SCOTT: Okay. But the quantum of government provision through you is equivalent to - - -

MR LO RICCO (ABINSW): $6000 - - -

MS SCOTT: - - - $6000 whereas in fact the level of intervention that is ideal would be the equivalent of 30,000?

MR LO RICCO (ABINSW): Or more, arguably.

MS SCOTT: Okay.

MR LO RICCO (ABINSW): Yes, so - - -

MS SCOTT: Could you talk a little bit more about that, because if the government says that - government says that you need a wheelchair, they might get you to wait for 18 months, they might provide you with a basic wheelchair but at the end of the day it looks like a wheelchair. I guess what I'm trying to elicit here from you - we haven't had many people provide evidence on autism issues, by the way.

MR LO RICCO (ABINSW): Okay.

MS SCOTT: What I'm interested in finding out is the government says this is a good therapy and supports it but it says it's a good therapy and supports it, "but you pay three-quarters of it and we'll chip in the remainder". I just want to get what the logic of the government only providing 6000 is.

MR LO RICCO (ABINSW): The logic for the government, I think - if we can take a step back. I think the fundamental problem with disabilities in this country at the moment is that there is a pool of money and we try and distribute that pool of money to as many people as we can who are deserving, and nobody can argue with that. That's the only way you can do it. There's only a small pie. We need to do it.

The fundamental thing that I would like to see come out of this Productivity Commission to some extent is to ignore money and to say, "Okay" - to identify, and there has been some discussion this afternoon here around what is the minimum level of support that needs to be given. I think that's where the focus needs to come from, how we fund it is a separate issue subsequently. I'm a firm believer - that's how we got ABI up and running. We said, "No, what do we want to do," and then we worried about where the money came from. I just think that's the only way you can approach business, to be honest with you, is just to actually go and say, "This is what we want to achieve."

Now, in the context of autism and early intervention there is a lot of debate over what is the minimum level of support. I must say right now, up front, I'm an accountant by trade, you might be happy to know that, John. I'm not an autism specialist. So I do slightly hesitate in some of the comments that I make here and I encourage you to go away and confirm them. The government - the state government and the federal government have both commissioned reports looking autism intervention and the level of support that is required. My reading an interpretation of that document is such that the government has concluded that when it comes to autism you need early intervention, you need autism-specific intervention and you need at least 20 hours a week. The government at the moment does not fund 20 hours a week.

MS SCOTT: Okay.

MR WALSH: Can I ask a question on that please, Sam?

MR LO RICCO (ABINSW): Yes.

MR WALSH: We've got the $6000, that's Commonwealth money, from my understanding?

MR LO RICCO (ABINSW): Correct.

MR WALSH: But you said that New South Wales - the New South Wales government supports ABA .

MR LO RICCO (ABINSW): Yes.

MR WALSH: Do they make a financial contribution to that?

MR LO RICCO (ABINSW): We have state government programs where they fund us $6000, yes.

MR WALSH: So that might make it $12,000?

MR LO RICCO (ABINSW): No, under the terms of the contracts we can't marry the two together.

MR WALSH: Okay.

MR LO RICCO (ABINSW): In fact - - -

MR WALSH: So you only get one lot of $6000.

MR LO RICCO (ABINSW): Yes, you have to go - practical matter is that we will take intakes through state government and do a program for a family which lasts $6000 over six months and then eventually we will bring people through again with repeated programs or partial programs with Helping Children with Autism.

MR WALSH: So the $6000, that's not per year, that's a one-off?

MR LO RICCO (ABINSW): That's a one-off funding, yes.

MR WALSH: Okay. What you're saying, I think, is that the ideal intervention is 30 to 40 hours a week?

MR LO RICCO (ABINSW): What I'm - I'm not making - I don't feel comfortable making comment that it should be 30 or 40. What I say is that's what my son got and I believe that he is the best that he can be today.

MR WALSH: Yes.

MR LO RICCO (ABINSW): What the reports that the federal government and the New South Wales state government commissioned - my understanding of those is they say 20 hours.

MR WALSH: Minimum of 20?

MR LO RICCO (ABINSW): Minimum of 20 hours.

MR WALSH: For how long?

MR LO RICCO (ABINSW): For at least two years.

MS SCOTT: Sorry to labour this point, so be slightly patient with me.

MR LO RICCO (ABINSW): No, no, totally.

MS SCOTT: The government funds $6000 worth of ABA therapy but the $6000 doesn't buy you the 20 hours a week for two years.

MR LO RICCO (ABINSW): No. It's a very, very different program. The program that we put in place very much relies - it's a more family-centred model than a traditional ABA program. A lot of intervention programs come that are very curricula-based.

MS SCOTT: Yes.

MR LO RICCO (ABINSW): So they impose curricula. We can't do that for $6000. What we do is we have developed a slightly different program where we transfer and empower families to skill them up to problem-solve for themselves the issues and teach the children.

MS SCOTT: Okay, yes.

MR LO RICCO (ABINSW): Okay? Yes.

MS SCOTT: All right.

MR LO RICCO (ABINSW): So it's very, very - fundamentally different program.

MS SCOTT: Okay, we're making progress.

MR LO RICCO (ABINSW): Sorry.

MS SCOTT: No, it's fine.

MR WALSH: No, this is an important issue.

MS SCOTT: You're doing very well.

MR LO RICCO (ABINSW): Okay.

MS SCOTT: I'm being a little bit slow this afternoon. For your son, for James, it was ideal that he got the 30 or 40 hours a week and he got four years and you can see the transformation in him and he is much better for that intervention. You are pleased with the investment that you made, it was a very considerable amount of money. For people who are looking for an ABA-type of intervention, a model they can access through your organisation - have I got that right?

MR LO RICCO (ABINSW): Yes.

MS SCOTT: With a lot of family input where they're effectively the stand-in therapist - I'm going okay so far?

MR LO RICCO (ABINSW): Yes, fantastic.

MS SCOTT: Is it they are trained and they then turn around and use that training in their family to achieve the results. Yes?

MR LO RICCO (ABINSW): Correct.

MS SCOTT: The government funds $6000 for that?

MR LO RICCO (ABINSW): Yes.

MS SCOTT: Okay, thank you.

MR LO RICCO (ABINSW): Yes.

MS SCOTT: I've got that.

MR LO RICCO (ABINSW): Perfect summary.

MR WALSH: Can I ask - just need to understand this one. So 30 or 40 hours a week or even the 20 hours a week, is that one-to-one?

MR LO RICCO (ABINSW): Yes.

MR WALSH: That has to be one-to-one?

MR LO RICCO (ABINSW): Look, I can't remember what the reports would say.

The nature of - it depends on the functionality of the child and their developmental stage, I would have to say. Obviously one of the deficits that exists with children with autism is one of a social disorder. So how are you going to address social disorders if you just do one to one? So no, it doesn't only need to be one to one. Perhaps in some cases still one-to-one guidance but in a group setting with children of more neurotypical behaviours.

MR WALSH: In your view what are the shortcomings in your model? I mean what's the sort of $6000 - - -

MR LO RICCO (ABINSW):   The ability - it's a hard one. The ability of different families to cope is the fundamental difference. A lot of families cannot cope, as you can imagine, when they first achieve a diagnosis with the children and depending on their disability. All they want their child to do is stop banging their head on the wall. They don't give a damn about whether they're going to be able to speak. So the amount of work that any particular family can take on will vary. So some families embrace the programs like you can't imagine and throw so many hours into it and probably do 40 or 50 hours a week, but they happen to have the capacity to do that, other families can't.

For example, families of Aboriginal and Torres Strait Island backgrounds who have other issues, which I'd like to get to; families where disabilities, for example, are not accepted, culturally, who so therefore hide those disabilities so they don't get the family's support; so people of different linguistic backgrounds themselves who can't - it's difficult for us to deliver the programs for them, particularly because sometimes state government, not federal government - there's a lot of issues with translation services with state government. State government doesn't fund them enough. So it really depends, yes.

MS SCOTT: Sam, just one more point. I did have someone after our hearing was over speak to me but didn't fell comfortable about going on the record. She had mentioned ABA and said that - I think it's all right as long as I don't use her name to tell you briefly what she said, and that was that she and her husband had taken out a second mortgage in order to get this intensive therapy just for, I think, three months but it had made a remarkable difference. It was very much about them sort of acquiring all the knowledge that they could and all the skills they could in order to go on further. Is that a commonplace thing, if parents actually find that the 6000 does have a difference that they then want to go further but financial constraints stop them? Or do you find that most people say, "No, the 6000 made a difference and I'm happy with where we've got to. I can now take this on further myself?

MR LO RICCO (ABINSW):   Honestly, I don't know why, but I actually find that question a little bit difficult to answer. We have had families that have gone on and are doing an intensive program, yes. They may have been concerned by it, they've come to us and they've identified it as an appropriate form of therapy and they've moved and they've been lucky enough to do it. I must admit that I'd get very, very concerned if I was approached by a family to suggest that they wanted to mortgage their home. I'd find it very, very difficult to counsel them in that situation. My personal view, although it's up to people, is I wouldn't do it. Yes, I just wouldn't do it. Yes, it's a very awkward one. In fact I'd try and counsel people against it to some extent, although that's their own choice.

MS SCOTT: Okay, thank you. Well, we got as far as that. Just go on.

MR LO RICCO (ABINSW): Accessing super is another big one. A lot of people access their super, which again it is possible under the financial hardship provisions - you probably know better than me, John - under those, to access superannuation, and I am aware of a lot of people that have pulled all their money out of super for this. I find that actually quite heartbreaking, that they've felt themselves that they're in that position and they have to do it. They make the right decisions for themselves and their families but it leaves them short for later.

MS SCOTT: The $6000 version of this, how intensive is it? I mean, if a family had two or three children all of different ages and all the commitments that that brings, and they had, say, one career going on and one paid work, would they be able to manage doing 30, 40-hour intensive therapy a week?

MR LO RICCO (ABINSW): Look, it's very, very hard. I mean, I survived because I went to work all day and my parents basically - so there you go, nearly 70-plus-year-old carers looking after my children. That's where they are today, looking after them. That's the only way I've been able to survive. I couldn't have afforded it if I didn't move back into home with them and that they were able to provide the day-to-day care - that's where I said "practically". So basically I earnt my money and paid for the therapy.

MS SCOTT: Yes, thank you. Look, please keep going. That's very instructive.

MR LO RICCO (ABINSW): That's actually one of the critical points that I did want to talk about, if I could just make the point again, is that when structuring the scheme I think the first question to be asked is, What is the minimum level of support across the range? And then we worry about the money. The biggest issue that I see with introducing a scheme that we're talking about is, I think, the fundamental problem with the disability industry is there is no capacity in the industry and it is not only driven by lack of funds. It is driven by lack of workers, workers that burn out - you know, people who don't want to come into the industry, people who burn out in the industry. So its capacity is the biggest problem.

I guess the thing that I can liken this to, most likely, is the federal government's Helping Children with Autism package. You had a situation where the federal government threw a lot of money at autism, and specifically early intervention which is in our area. What actually happened in my view is that anybody who was paying for private services all of a sudden had $6000 in their pocket. You didn't see an exponential increase in the total capacity across the industry, and I think that is going to be the biggest challenge that we have with this scheme, which is where - and there was a debate earlier I heard about some service providers preferring block funding versus individualised packages - and that's the critical problem with an individualised package.

If I was to take us - and I'm sure every organisation is a little bit different - we're very small. I have 10 staff; three are on maternity leave. I don't how we manage through that process. But that is another issue. I mean, there are a lot of females that come into our industry and then you lose them for five or six years and that's just the function, which is fine. For us, I can't hire a speech therapist and throw her out to deliver a program or an OT or anything like that. I can't just hire a professional and say, "Go out and do your stuff." It doesn't work that way in my mind. We run a program which is a particular model and it takes me, depending on the experience of the person - well, not me, the staff - something like four to six months of practical training to bring them up to speed so they can go out and implement the program.

I have a cost of training somebody of about 20 or 25 thousand dollars potentially, because basically they have to shadow somebody before I - because we're a home-based program, we're not a centre-based program, so we go to people's homes. We go to their pre-schools, we go wherever they want to go - church, whatever - and work with them in those settings. So I can't just send anybody out to achieve a goal, they have to be appropriately trained. So I'm after a highly skilled person. Individualised packages are fine but I need that $25,000 up front to train somebody before I can deliver more programming and that's an inhibition on our ability to grow. I'm not worried, block funding-personalised service funding, because I'm very comfortable - I'm sure most people are - that they run a good - if you run a good service people are going to come to you so it's not a problem.

The issue though is that we, as not-for-profit organisations, don't have share capital, we don't have capacity to go out and borrow from banks or other things so we have to rely on our cash flow and you can't rely on cash flow to invest and build an organisation. So some level of infrastructure support to organisations is going to be critical in order to deliver this program. I'm not quite sure if this is the right forum, but I actually question why - that is so obvious to me that I don't understand why the government actually hasn't already committed that expenditure in preparation for a scheme that we know is going to come in, it has to come in.

MS SCOTT: Well, maybe you might want to contemplate about any subsidy paid at any time on anything - first home owners scheme, child care subsidy. I think you're probably dealing with the same issues. Maybe we can talk about that later, but it is certainly a very important question that you're putting to us, this issue of how do you find the extra capacity. We know we've got unmet demand, we know we've got under-funding, but if you suddenly inject additional money one of the issues we've raised in the issues report is how do you find that that doesn't just get absorbed in extra overheads or wage inflation or whatever, because we actually clearly want additional resources. So, look, we might have a chat afterwards. Is there something else - I know we've spent a lot of time in getting our heads around autism.

MR WALSH: You wanted to talk about indigenous - - -

MR LO RICCO (ABINSW): Well, I've sort of made that point. I think the issue which I've covered - we noted that probably over the last three years we've worked with over 300 families and we've done two children from an Aboriginal background. Now, we don't manage our intake so I'm pretty comfortable it's not that we're - that's actually managed by ADAC so we sometimes get the worst of the worst, the ones that haven't got any services. We went trying to find out why is it the we only got two out of 300 from Aboriginal background and that's where I made the comment earlier about certain cultures not wanted diagnoses. My understanding is - and there are better people than me to comment on this and I encourage you to go out and source those people - that there is a reluctance from people from an Aboriginal background to get a disability diagnosis.

We have as one of our conditions for intake is that you have to have a formal disability diagnosis of autism, so Aboriginals are not able to access the service and that somehow needs to be managed. You have similar issues across other cultures. We worked with a family from Sri Lanka who refused to tell their family and their community that the children have autism.

MS SCOTT: Yes, that's a good point. Sam, thank you very much.

MR LO RICCO (ABINSW): Can I just make one other comment. The other comment that I wanted to make was with regards to the quality of services. Wherein the organisation and my involvement in the industry is new, I have a concern that the government's focus is too much on how many services they provide - tick, tick, tick - what the cost was for the provision of the service - tick, tick, tick - which is very easy to manage because you just drop the level of service. Nobody ever questions us about, what are the outcome of our children, what did we actually do? You went in to run a behavioural program for them. What were the behaviours at the end? How did they deal with them? Nobody has ever looked at our outcomes, nobody wants to know.

I am concerned as a taxpayer, as a parent who's accessing services although I happen to not access any government-funded ones, and I know my staff find that quite frustrating because they feel that their service is not being valued. They achieve these great outcomes but they're evaluated really, "Oh, okay, yes, you did another unit and you delivered the right number of hours at the right cost - tick, tick." They don't want to be evaluated that way.

MS SCOTT: Yes, okay. Well, that's very useful - good point.

MR WALSH: It's a good point.

MS SCOTT: All right. Thank you for the material. Are you going to be making a formal submission, Sam?

MR LO RICCO (ABINSW):   I will be, yes.

MS SCOTT: All right. Sam, you've seen the level of unfamiliarity with this subject. We've got to get our heads around an awful lot of material - financial, behavioural, early intervention - so if there's an easier way to approach this subject we'd certainly welcome your assistance to that.

MR LO RICCO (ABINSW):   I will make a formal submission. If you have any questions or would like to be put in touch with some additional organisations or other who for whatever reason have decided not to make a presentation, I will do my best to bring them to the table.

MS SCOTT: Thank you very much, that's very good. Thank you.

MS SCOTT: I now welcome Tim Smith from Fortitude, please. Tim, for the record could you just give your full name. I understand you're representing Fortitude Parents Group. If you could make an opening statement that would be good.

MR SMITH (FPG): Yes, so Timothy Smith. I'm the secretary for Fortitude Parents Group. We're a fairly new entity. We started about 12 months ago. Our primary focus was as a support group for parents with kids with special needs. At the start of this year we extended that remit to include advocacy work due to the challenges that a lot of our members were facing. Our focus is not on specific challenges that children may face or young adults or parents may face that have additional needs, our focus is really on supporting the parents in their challenges around funding, delivery of services and also sort of just helping their children be the best that they can be and achieve the most they can be. Our particular focus at the moment is predominantly on children, so people under the age of 16; that's where most of our policy frameworks are focused and that's because that's the majority of our membership, which is just shy of 100 members now, sit in that area of - that's basically where their children from an age point of view at this point in time.

At the end of the day our focus is really not so much on wholesale change. Our focus is really on, how can we enhance existing legislation that's currently in play to provide short to medium-term benefits to reduce both emotional and financial stress associated with caring for a child with special needs. We see things like the National Disability Insurance Scheme as a great long-term way to address some of the broader challenges for people with disabilities; however, there's still a lot of people under a huge amount of stress that need help between now and the next five to 10 years when such a scheme is likely to come into play. So from our submission that we provided to you previously the focus is really on what are the short-term things that we can do that will have a tangible benefit on parents caring for kids with special needs.

MS SCOTT: Thank you. What's the sort of time frame for the extra measures that you're interested in? I mean, a number of them are tax concessions and so on, and a conditional payment, I think, from memory. In what time frame do you think they could be introduced?

MR SMITH (FPG): Realistically, they could quite easily be introduced from next financial year if the government decided to act on them. The likelihood - our view of a short-term benefit is three years. So we commenced this program at the start of this year, so if we can start to see some of the particularly funding support elements - so the first three elements, which are actually fully costed as well in the latter half of this document - if we can look at introducing them within three years we see that as a realistic outcome. The challenge with these things is funding. There are three key things that we think in the short-term would help.

The first one relates to child care. If you've got a child with special needs the challenge is you cannot get full-time care. To give you background, my son is profoundly disabled. He as a rare chromosome deletion. That means that he can't talk, can't walk, hearing impaired, intellectual developmental and global developmental delay - so physiologically as well as emotionally and intellectually. We can only get two days a week worth of care for him and that has taken us two years to get of fairly - I mean, we even had to take our local council to the Human Rights Commission to help them find care for us. The challenge is it means that most parents with kids with special needs rely on nannies or one of the parents is unable to work. Now, unfortunately that's unacceptable.

If you look at the Australian Bureau of Statistics, on average a household with a child with a special need will earn 16 per cent less than a household that doesn't have a child with special needs. Now, if you extrapolate that over a working life, assuming that the parent is about 30 when they have the child, based on an average income, that's $1,000,000 worth of lost income and $100,000 less super. That is not insubstantial. One of the key things that we sort of really think is important is access to the child care rebate. If you use a registered carer or a registered nurse for care for a child with special needs you cannot access the child care rebate because it's not seen as a formal child care service by the Family Assistance Office.

MS SCOTT: I imagine people have advocated for this change previously. Have I got that right?

MR SMITH (FPG): I met with Kimberley O'Brien, who is the child care adviser within Kate Ellis' office and when we presented this, and also at the time with the assistant secretary at DEEWR for early childhood programs, there were blank stares on the face. So it certainly with them didn't seem like it had been something that had been pushed heavily.

MS SCOTT: Okay.

MR SMITH (FPG): The variable carer allowance had been previously put forward and had been in one of the previous - it was actually recommended in a previous report that had been commissioned by the government but they chose to ignore it and they couldn't explain why. That was Abbie Clark who I discussed it with, who was the carer allowance adviser within Jenny Macklin's office.

MS SCOTT: Okay, all right. Well, that's good. That's good leads, thank you. I guess the distinction is that because one parent is forced to be at home or chooses to be at home, that means then they're not eligible for the full amount of the child care rebate because effectively they're providing the child care.

MR SMITH (FPG): Yes, exactly.

MS SCOTT: So you'd want the option that the child care rebate is available if a family engages a carer or a registered nurse because of the special needs of the child.

MR SMITH (FPG): Yes.

MS SCOTT: You'd only require the special needs of the child to be assessed by, say, a doctor. The assessment is already done, tick that box, and then you're eligible for this.

MR SMITH (FPG): Exactly, yes.

MS SCOTT: Okay.

MR SMITH (FPG): Senator Mitch Fifield helped with some Senate Estimates numbers for us which are in this documentation. Basically for children under the age of 16 that are on the carer allowance with a recognised disability, we're talking about 83,000 families. Unfortunately, it is a real minority within the Australian populace and it means that there aren't many votes in it. So the population for that additional support is relatively low. A number of them are already getting access to the child care rebate; for example us, with our son in two days a week worth of day care.

MS SCOTT: Please power on.

MR SMITH (FPG): The second piece of the puzzle is a variable carer allowance. The idea here is that it's an existing piece of legislation. Again you see that's fairly common with everything that we put forward within our policy frameworks. The challenge is that if you've got a child that's profoundly disabled, or mildly disabled, there's a fairly wide swing associated with your care costs looking after that child; with probably one exception, which is autism, where if you're doing something like ABA therapy the cost associated with using private ABA therapy are quite significant. We have some members that are spending close to $80,000 a year on autism therapy for their children, and that's a child who would probably be diagnosed more moderately disabled, if you look at the Griffith model of mental disability, it's the exception to the rule.

MS SCOTT: How do they finance $80,000 a year for therapy?

MR SMITH (FPG): Fortunately, with this particular family within our group the father is [a senior executive with a major company and is on a significant salary], so that makes it achievable. The problem is that 99 per cent and the rest of families out there do not have that level of financial support behind them to be able to do that, and that's a big challenge. What we're saying is, in our instance, if you look at the example at the back of the document at actually some high level snapshots of the financial implications of caring for our child: we spend $90 a week on physio, and that's just a private physio, we also have a speech therapist, we also have two occupational therapists that help with support.

All of them are privately-funded because we are unable to get any level of OT or physio support from the New South Wales department dealing with disabilities. The reason for that is because we have gotten private support they refuse to provide public support for the child. You sit there going, "So because we actually went and got extra support you will not provide us with OT or physio support?" That was the answer, "Yes, we will not provide you with that support."

MS SCOTT: Sorry, I just want to check this. I don't want to go away and have a different recollection. So because you're actually providing some of the therapies out of your own pocket you're ineligible for publicly-funded therapies"?

MR SMITH (FPG): Through ADHC, yes. They won't put that in writing for us, because we were going to go to the minister about that, but in over a year of engaging with our case manager they have not provided us any departmental-based - - -

MS SCOTT: What public explanation do they provide, Tim, for that?

MR SMITH (FPG): Because we have sourced private physio and private OT there is not a need for them to provide public.

MS SCOTT: Let's pretend I'm them, "We do things on assessed need. Tim, we know that you're already getting the need you require, privately, so why would we fund it?"

MR SMITH (FPG): Because there's more than just what we provide that the child needs. My view is that the more intervention services you can deliver within the first five years of the child's life the better the care outcome in the long term and the less burden that that child is on the government over the course of their life.

MS SCOTT: I understand that.

MR WALSH: So your argument would be that the private investment you put in should supplement the government services to make an overall better outcome?

MR SMITH (FPG): Yes, it can't hurt. The more intervention services we can give children with special needs the better the outcome for that child. So my view is we should throw everything and anything we can possibly at that child to try and deliver the best outcome.

MS SCOTT: A model the Productivity Commission often brings is an exercise of cost benefit analysis. It sounds very hard and cruel, but - - -

MR SMITH (FPG): No, it's perfectly fine.

MS SCOTT: I'm not saying I agree with what the state officials have said to you. In fact I'm sort of surprised what they're saying to you. But it's okay, I just want to get a handle on it. If it turns out that your child only needed three sessions of physio a week, maybe they could come to the view that three is about the right number and five is not. You're saying you'd like to throw as much activity into this as possible and that five days of therapies could be great, two days is insufficient. In your view, is there ever a point where the costs keep going up but the benefits start flattening out?

MR SMITH (FPG): Of course there is always a point where that happens. But if you take a step back and look at the types of therapies available, accessibility is a problem. Hyperbaric chamber treatments, which is a mild hyperbaric chamber, has shown to be exceedingly beneficial in US based testing for children with autism or children with speech development issues. Marcus, in our instance, does not have any speech function, and hyperbaric chamber treatments can actually help with frontal lobe stimulation, which can result in a better ultimate care outcome. Those sorts of services are outside our means because they have to be privately-funded.

To give you an idea, we're talking to get a chamber in your home it's about $22,500. To do a single treatment it's over $100. Some of these treatments are not available. Also, within occupational therapy you've got a variety of different areas where development can be assisted. So you've got traditional sort of sensory style or proprioceptic style treatment, you've also got sort of general interaction, you've got a variety of ways of doing speech therapy. So having the ability to leverage on a broader range of services will ultimately provide a better care outcome.

Our suggestion here is actually the more profound the child's disability the higher the costs are likely to be because you've got more services being funded. By increasing the carer allowance to be based on the severity of disability it would allow the parent to have that greater level of cash flow to be able to privately-fund more services, which also alleviates load on the state government system as well. Does that make sense?

MS SCOTT: Yes, I understand.

MR SMITH (FPG): So there is always going to be a point where you max out. From the point of view of Marcus we have five different pieces of therapy during the course of a week and he copes very well with that. We still have a very long journey, because he is so on the profound level of disability. But he is still a beautifully content little child.

MR WALSH: If you have any evidence or any literature on the sorts of interventions that you're providing, that would be useful.

MR SMITH (FPG): Yes, I will see what we can produce.

MR WALSH: Can I just ask a question. Most of your suggestions for the scheme seem to be around enhancing allowances and tax deductions and the Medicare Safety Net, and there's almost an implicit assumption in there that if you improved your cash flow the services would be out there to purchase and the service network is okay. Is that your view of the services?

MR SMITH (FPG): There's three key elements that we see that are important. Access to services, access to equipment, and then access to early intervention capabilities. The services side of things, for example funding support for child care, the primary purpose for that is employment participation. So the idea is if you can get better funding of things like child care, through the use of nannies or registered nurses, you can increase your workforce participation, increased workforce participation helps reduce financial stress within the household, which reduces emotional stress, which should have a positive impact on divorce rates within families with special needs, but also provides more cash to be able to do more things.

The access to equipment is a big issue. Trying to get any equipment out of the state government is like extracting a tooth with a pair of tweezers, it is not a very practical thing to be able to do. We have from our personal point of view been spending over a year to just try and get a high-low bed because my son is 113-centimetres tall at four, he weighs 25 kilos and he does not walk. He also has hypotonia, so has low tone, so he is very floppy. It has been 12 months, and we have been told, "Within the next six to 12 months, if you're lucky, you'll be able to get a hi-lo bed." If that item was tax-deductible, rather than just a small portion, potentially being able to use the Medicare Safety Net, we could potentially look at purchasing that ourselves.

MS SCOTT: I'm sure the bed actually costs more than the Medicare allowance. The Medicare out-of-pocket expenses is a tiny fraction of the cost of the bed? Is that what you're saying?

MR SMITH (FPG): Yes. So for example for a hi-lo bed for our son we're talking about $12,000.

MS SCOTT: Okay, I have got it.

MR SMITH (FPG): So if we get 20 per cent of that back, hey, fabulous. But if we then look at getting another 45 per cent of that back as a tax deduction on that piece of equipment, it would make it a no-brainer for us to look at purchasing that ourselves, because you can take out a small personal loan to be therefore able to fund that. At the moment my son is in a 120-centimetre cot-bed. We have to lie him diagonally because he's starting to outgrow that, and it's another 12 months before we're likely to get access to that equipment.

A lot of our things are really simple practical things that are designed to help the short-term challenges, that start arguments within a household. Access to equipment, access to money to be able to offset some of the costs associated with care. Like I said, last year we spent $45,000 after tax, out-of-pocket on care-related services for our son, and that was after the carer allowance, that was after any tax benefits we were able to get. The biggest chunk was nannying, which was $30,000 out of pocket, with not a cent back from the government.

My son had a registered nurse for six months because he was epileptic and was having 10 seizures a week, prior to us being able to get the seizures under control. We weren't able to get a cent back for that because the nurse was not provided through a registered nursing service, we contracted them privately. The reason why we contracted privately is because it was substantially cheaper even with any Medicare Safety Net benefit than having to go through that service.

If you look at in-home care, which is what Kate Ellis has regularly recommended we do, to get access to in-home care today for my son is $44 an hour, and we get 50 per cent of that back up to $7500. We would go through that $7500 within four and a half months of getting access to that service, and we'd be close to $60,000 worse off if we actually went down that path.

MR WALSH: From where would that in-home support be purchased?

MR SMITH (FPG): People like in Sydney In Home Care provides those services. If you want to get access to the $28-an-hour service it's a 13-month waiting list currently. If you want to get access tomorrow, which is usually what you need, it's $44-an-hour service. That is eligible to the child care rebate, because that's viewed as formal child care or approved child care services. If you get a registered nurse or a registered carer, that is viewed as what they call CCB-informal, even though it's not written anywhere, and you don't get access to the child care rebate for that service. But that will cost you usually $18 to $20 an hour instead.

A lot of our focus is really on helping ease some of the financial burdens that the parents face, because that allows better employment participation, which allows more money into the household, which therefore allows access to better services. From an intervention point of view, depending on what your child needs, there is accessibility. Autism services are getting better but there's still a long way to go. Physio services are relatively accessible. The challenge is that as a general rule you can't take a child who is severely-disabled to a physio very easily. We have a private physio that comes to us three days a week, and that makes it manageable. There is always going to be some challenge with services. The bigger issue is the financial limitations rather than the actual accessibility.

MS SCOTT: One of the features of the existing arrangements around the Commonwealth and states is the complexity of them and the red tape and very prescriptive rules that people butt up against and so on. I appreciate what you're suggesting here is a series of measures that you think would provide some short-term relief for people while a larger scheme is rolled out, it's not impossible to imagine that a larger scheme - depending on its design and what the government finally does - could provide the bed, provide therapies, provide the attendant care and so on. Would you want these measures to be introduced and phased out if the scheme has those measures, or do you see particular advantages in having things paid for by the tax system rather than on outlays?

MR SMITH (FPG): Good question. It all comes down to the quality of the care outcome. If the government is able to facilitate care outcomes that are practical and useful, then by all means we're happy to see some of the funding support elements phases out. If they're not able to deliver that service outcome, then it's a very different conversation. So it's a difficult answer.

If you look at Brazil, for instance, they have got a very good approach to providing early intervention services, where you have a facility that you can actually take your child to on a regular basis to get all of those intervention services. Our physio is actually Brazilian and used to run one of these facilities for the government. In that instance, fabulous, because you have got the physios, you've got the OTs, you've got the speech therapists all on site and you can build a program which helps the child get the best outcome. I hold an optimistic sort of viewpoint, but I'd be surprised if we get to that point.

MS SCOTT: Tim, how long did it take you to get on top of this system, and did you ever think that such a system existed before you had reason to encounter it?

MR SMITH (FPG): On a personal front, we're probably about a third of the way through, I'm assuming. So there's a lot of things that we don't know. One thing we do as part of the Fortitude Parents Group is share information. So for example with referrals for your medical, you can actually ask your doctor to make an ongoing referral, but no-one tells you that. The doctors don't want to do it because it means you're not going to come every six months for a new referral and pay your $80. It has taken us four years to get to where we are.

The policy framework itself took about six weeks' worth of effort, collective from our group members. You have got tools like Through the Maze, but it's a 60-page document and it's just too hard. One suggestion we made is a case manager that can help you navigate all the different things. But a case manager needs to stem across both the state government and federal. The big issue we run into is that you've got so many departments with which you need to engage - and I see a few nodding faces out there.

You've got FaHCSIA, you've got the Tax Office, you've got DEEWR, you've got the ADHC in New South Wales, you've got the Department of Health, within Department of Health you've got PADP, you've got EnableNSW. There are so many fractured elements to actually address this problem. You talk to Bill Shorten, or Julia Thomson and Mat Tinkler, the advisers for Bill, and it's like, "Well, no, that's not my area. We look after the state government interaction and the Special Disability Trust. So you need to go to Abbie Clark if you want to talk carer allowance. You need to go to Kimberley O'Brien if you want to talk child care rebate." Having somebody that's able to actually pull all these pieces together would make life a lot easier.

MS SCOTT: Do you think a person exists like that? Do you think anyone has actually got the helicopter knowledge of the system?

MR SMITH (FPG):   I think we have got the framework in place in the way of the Family Assistance Office. If you talk to a senior consultant within the Family Assistance Office they have actually got pretty good cross-departmental knowledge. If you talk to a junior person there, you're ready to slit your wrists - pardon the fairly direct comment - because - - -

MS SCOTT: No, it's all right.

MR SMITH (FPG):   - - - because you usually get misinformation where you then spend 40 hours filling out paperwork and then find out that you're not eligible for that funding; as we found out with the child care rebate, the hard way, after I filled out 36 of the 42 pages of documentation. I think there is the facility with the Family Assistance Office to be able to provide that, but it requires a broader scope, and also it means more than just a call centre, it means actually allocating parents to specific individuals within that facility. But it is achievable and it is there, it just needs to be enhanced.

MS SCOTT: I understand. Tim, thank you very much. I noted your submission earlier in the day in terms of chancing your arm on costings and so forth. So thank you very much, and thank you for coming along today.

MR SMITH (FPG): The costings are all based on senate estimate committee data as well, which I think is important.

MS SCOTT: I think I will get Hudan to particularly mention that to our team leader, because it adds certain information to it. Thank you very much.

MR SMITH (FPG): There's a very simple funding model in here as well. If we look at indexing across the government and everybody shares a bit of pain. So the idea there is if we pause indexing across all departmental policies for a two to four year period you actually get a big enough pool of funds to be able to implement a lot of these enhancements.

We have done an estimate here with it, just saying, "If you took a $4 billion dollar freeze of indexing" - which is a significantly smaller amount, I haven't even been able to get to the number, it's getting that big - "you'd be able to pay for $1.2-billion worth of additional support for parents with kids with special needs, whilst waiting for a broader disability scheme to be established." It's a very easy approach. The only problem is again it's across multiple departments and ministers don't like giving out money from department to another, again a problem of a fractured environment. Thank you very much for this opportunity.

MR WALSH: Thanks, Tim.

MS SCOTT: I asked earlier was there anyone who wished to make an impromptu comment. I heard then that there wasn't. Just confirming that, that there is no-one who wishes to come forward at this stage? All right. I now adjourn the hearings. Thank you very much for attending and for your attention today. It's very encouraging.

AT 5.03 PM THE INQUIRY WAS ADJOURNED UNTIL
TUESDAY, 20 JULY 2010