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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, Commissioner

TRANSCRIPT OF PROCEEDINGS

AT MELBOURNE ON TUESDAY, 8 JUNE 2010, AT 9.11 AM

Continued from 7/6/10 in Hobart

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MS SCOTT: Good morning, welcome to the public hearings of the Productivity Commission inquiry into Disability Care and Support. This is our second day of hearings, we commenced yesterday in Hobart, and we have another day tomorrow in Melbourne, and thank you very much for attending today. My name is Patricia Scott and I am the presiding commissioner of the inquiry. My fellow commissioners are David Kalisch and John Walsh, and John will be joining us later after morning tea through modern telecommunications, through Skype.

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 cost of long-term care, replace the existing funding for those people 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 submissions have been coming in to the inquiry following the release of our issues paper in May.

We are grateful for the submissions already received and submissions can be downloaded on our web site, www.pc.gov.au. While we would like to get submissions as early as possible, in view of the concerns raised by some participants, the commission has extended the due date for initial submissions to Monday, 16 August 2010. So if you haven't heard about the extension in the deadline, it's 16 August. The commission also welcomes second or even third submissions, you can even go for fourth submissions, you can put as many in as you like.

These submissions may include additional points you wish to make, comments on other people's submissions and results of community consultations. The purpose of these hearings is to provide an opportunity for interested parties to address their submissions and their views and to put those views on public record. We will be holding hearings in all capital cities, depending upon demand. The hearings commenced yesterday. We will be conducting hearings into July.

We will then work towards completing the draft report in February for public comment and we will invite participation and another round of hearings after that time, after people have had a chance to read our draft report and our draft recommendations. We like to conduct all hearings in a reasonably informal manner, but I do remind participants that a full transcript is being taken, and that accounts for some of the technology and the gaffer tape around the place. For this reason, comments from the floor cannot be taken, but at the end of our proceedings I will provide an opportunity for anyone who wishes to make a comment to come forward and make a brief presentation.

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. The transcript will be made available from the commission's web site following the hearings, and I would ask you to take the opportunity now to turn your phone onto silent or off, so we don't have interruptions into the hearings. Are there any media representatives with us here today? Could you please identify yourself? No. Okay.

Safety. To comply with the requirements of the Commonwealth Occupational Health and Safety legislation, you are advised, in the unlikely event of an emergency requiring evacuation of this building, please follow the instructions of the hotel staff. If you require assistance, please speak to one of our inquiry team members here today. Ineke and Ralph, they're at the back there, identify themselves. I would like to welcome our first person presenting today, Chris Monteagle. Please come forward, Chris. Thank you for coming along.

MR MONTEAGLE: Thank you very much.

MS SCOTT: Chris, could you just identify yourself and if you're representing yourself or an organisation.

MR MONTEAGLE: My name is Chris Monteagle. I'm representing myself and my direct family.

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

MR MONTEAGLE: Yes, I would. Thank you, commissioners for this opportunity to put forward my views, based on my own experience. I have put together a fairly comprehensive overview of our position on the web site already, but I'd just like to draw your attention to a few key points today that are of most concern to myself and my family; most of all it is the lack of in-house respite that we find in our day-to-day lives. In our situation we have a young daughter who is four years old, just about to turn four, with a very serious disability, and we also have a young child who has just turned two.

The pressure of giving your special needs child attention, or the right amount of attention, competes on a daily basis with your other duties as a parent, and that is one area that I feel gets overlooked. You're often assessed on the number of children with disabilities that you have or the severity of the disabilities, which is fine, but competing priorities and competing pressures, often psychological pressures, do not get recognised, and I can speak from personal experience when I say that my wife finds it very difficult and encounters a lot of guilt when having to balance those competing priorities. So I'd like to make that point.

The second point I'd like to make is around our level of service. I believe that, whilst we have good people out in the community doing a lot of good work, we need to have a case management system that provides a guaranteed level of service to carers out in the community. What I would ideally like to see is something not dissimilar to a service level agreement whereby if I'm a parent and I make a phone call about a walking frame for my daughter I can make a phone call to one area and I will get a call back within a certain amount of time, even if it's just a call back to say, "We don't have any information for you yet."

What we find is that we're not only making multiple calls to different areas but we have to continuously chase up these people because they're on part-time work or they're busy doing other duties, and there's no accountability there. I'll come back to that point in a second. Around cost, I'm sure this is going to be spoken about a lot of times today, but I'll put in my two cents' worth. It says in the discussion paper that, "Informal carers and people with disabilities bear too much of the costs associated with disability." Now, in my view, that point can't be overstated.

You feel like you're neglecting your child if you rely solely on public-funded support. Essentially, you have to contribute out of your own pocket, if you want to give your son or daughter the requisite level of support that you feel they need to get moving; and that's not just a parent being overly anxious. I'll give you an example in a few minutes about how much service we're receiving versus how much service we're supposed to be getting. So with that gap in mind, we very strongly believe that the benefits should not be means tested. Disability, obviously, doesn't discriminate among financial position, so neither should our support of it.

If I, as the father of a disabled child, choose to work harder, work a second job, to get more money to get more support and resources, should I then get penalised for doing that, for showing that additional effort? I really don't think that's fair. So I'd like to make that point very strongly. Coming back to what I was mentioning before, around the financial impact, we're currently receiving one visit every two to three weeks, and that will waver, and sometimes those visits will get cancelled, for legitimate reasons, but they won't get rescheduled, due to competing priorities, because if we get ours rescheduled, another child will miss out.

Our private assessment, which we're now starting to fund, objectively assess that Laura, our daughter, needs two visits a week in order to start making up ground So at the moment, if we don't do that she's slipping further and further behind and won't integrate into society at all as an adult. Secondly, my daughter has had what's called a hemispherectomy by the neurosurgeon that separated the twins in the media last year, which means she has had half her brain removed.

She has autism, that's clear. However, we need to get an assessment. It's going to take six months on the public waiting list. Now, this is an area where early intervention is critical. So once again we're going to fund this ourselves, but that means that if we were to rely on the public system she'd be five before she could start to get treatment. On those out-of-pocket expenses at the moment we believe - well, we know that Laura needs two sessions a week of therapy. So we're paying 200 bucks a week after the Medicare rebate out of our own pocket to finance that. It's also going to cost us somewhere between 600 bucks and a grand to get the private autism assessment. That's just May and June. I'm not exaggerating that. I'm sure there's going to be plenty of other stuff down the track, but that's just to give you a view of the pressures that we're facing at the moment.

I believe that we need a minimum standard. As you'll see in my submission, when we were in qld - and I don't know this is - the Queensland Cerebral Palsy League were able to give us two therapy sessions a week: physio, OT, speech, and they were very flexible around that. We believe that's the minimum standard that the community should be receiving and that should be a firm and accountable service level. So if it's not happening the community needs to have a mechanism to enforce that and make the relative bodies accountable. And I don't say that as a criticism, because I recognise that the community groups are doing very good work, but we need to have greater support at a higher level that can give greater assets and greater resources to these community groups if we find there are areas of the community that are lacking. You'll see in my submission I've pointed out a few geographical areas where that's certainly the case. That's those points that I'd like to make and I thank you for the opportunity.

MS SCOTT: Thank you. David, would you like to lead off?

MR KALISCH: Yes. I suppose I'm interested in what you say about the differences in treatment options within Victoria itself, and you sort of point out a difference between east and west.

MR MONTEAGLE: Yes.

MR KALISCH: What's driving that difference? Have you got any idea?

MR MONTEAGLE: In Victorian, or in Melbourne at the very least, you are classified as in a particular region, and I'm sure there will be other people that are better qualified to speak about the governance around this. The bottom line for us is that we get to choose one organisation - Scope or Yooralla, or a number of others that are in our region - and then we're bound to their services. Now, bear in mind when we moved down from Queensland to Victoria last year it took us three months to get on the waiting list to one of these organisations. So if we want to swap, for whatever reason, we've got to go back on the waiting list. We know through personal experience - we have friends with disabilities that live out in Doncaster that are receiving far better services. When we inquire if we can get those too, we're told, no, we can't because we're in a different zone.

MR KALISCH: I suppose - I mean, you may not be able to answer this but is there any sense as to why people in a particular zone do appear to get better services?

MR MONTEAGLE: My understanding - and I'm sure other people will speak to this - is resources are allocated by these zones or whatever they're called. So if there are special schools, for instance, located out in Doncaster that pick up your kids and provide all sorts of services, if you're just not lucky enough to live in an area that has a similar facility, for funding reasons or whatever reason, the service just isn't there to be offered. Even if we were willing to say, "Okay, we'll drive our daughter out to our mate's school over in Doncaster and do that," we're not allowed to.

MR KALISCH: In terms of - I suppose one of your propositions to us was that the assessment of need and support that a family should receive should take account of, I suppose, the other care responsibilities, other care capacities, of the family. Is that - - -

MR MONTEAGLE: Definitely. I say that, as I said, with strong personal experience. My wife is actually being treated for depression right now because she does deal with that psychological pressure. I'm sure if you've got kids you know what it's like. When you've got a two-year-old and, as a mother, she unfairly feels guilt over what happened to Laura even though it wasn't her fault, it was just a one-in-a-thousand chance of a defect in the womb, the mother still feels guilty. So she feels this need to look after Laura and give her extra and extra support. But she's got another child over here that has the growing needs of a two-year-old. So how do you balance that? It's a lot of psychological pressure.

MR KALISCH: So your suggestion is that in any sort of scheme that is developed or pursued by the government, that they take account of, I suppose, the care capacities as well as the care constraints - - -

MR MONTEAGLE: Exactly.

MR KALISCH: - - - of the family, direct and sort of broader family.

MR MONTEAGLE: Correct. Not focus solely on those children that have disabilities but of the broader context of the family unit.

MR KALISCH: Yes. No, that sounds fine. Do you want to talk about any other features of the scheme that you think should be put in place?

MR MONTEAGLE: Well, I mentioned in the submission that I believe strongly in centralisation and the reason for that is because, as I said, we're in the unique position of having moved to Queensland for a couple of years after my daughter was first diagnosed and then we moved back here. The irony is that we moved back here to get surgery and treatment - Laura was diagnosed down here - and the facilities in Melbourne are second to none as far as the hospitals are concerned. But, ironically, the community-based support is far superior in Queensland. We had the Cerebral Palsy League that acted as a one-stop shop. For anything outside of the hospital we picked up the phone and called them and they would give us that level of service that I was referring to earlier. They would call us back, they would keep us up to date.

When we moved to Victoria - and I understand it's a similar situation in Sydney - the services suddenly became fragmented and, to be honest, I expected the opposite in a bigger city with more resources. So with that experience in mind I believe that you need a central body. I believe that you need to have that you need to have that body federally mandated so that if I move interstate I don't have to tell my story another time and I don't have to go chasing up resources. As I said to you informally before this started you go through life assuming that, okay, if I get cerebral palsy or a serious disability I'm going to get looked after. The reality is that, at the risk of sounding immodest, I'm a very proactive guy and I can go out and I've got the resources to find this information and do the good job for my daughter but I know that other people in the community don't have that, and they shouldn't need to have to go out and do that leg work. Someone should come to them and give them that level of service and take care of them, which isn't happening.

MR KALISCH: Now, the single point of contact is quite an interesting dimension. I suppose the one question I'd ask is, should that be sort of close to the community where people are located - that is, have sort of a single point of contact for a particular region rather than sort of a distant person on a telephone line from a call centre?

MR MONTEAGLE: Yes, look, that's an interesting point and I suppose there's pros and cons to both, because at the moment our case manager is local and obviously you have that face-to-face visit. In the submission I actually said that it should be a federal body and I still stand by that. However, I would agree that that case manager should be local - and I actually haven't thought this through in advance

- but solely because of our personal experience with our support workers that come on site to help us out. They get to see the situation, they get to know your needs. So, yes, I would agree that it should be close to the family.

MR KALISCH: So that the sense you're giving about sort of a federal scheme is more about consistency of service across the country.

MR MONTEAGLE: Of service.

MR KALISCH: And transferability.

MR MONTEAGLE: Exactly.

MR KALISCH: That was the other dimension you talked about - when families move across borders.

MR MONTEAGLE: That's exactly right. So you've got that ability to hand over the case in a holistic fashion rather than saying, "Okay. You're outside of our zone now. Off you go, figure it out for yourself."

MS SCOTT: Has anyone ever mapped out for you, Chris, the services that are available at different transition points for your daughter?

MR MONTEAGLE: To an extent but, like I said, it's varied between state. When she was initially diagnosed the hospital, Royal Children's, down here was very good and they take care of you for those first few weeks or months. Then you get put out into community support where you do get a representative. As I said, we're with Scope and we found that we do get information but it's very much drip fed to you, and that's not intentional and, like I said, it's not a criticism. But it's just that the information isn't managed. You ask the question, you say, "This is my need," and you get told, "Oh, by the way there's an organisation like Baptcare or there's a Lions Club," and we can go through these different channels. It's all very confusing but you always get the impression that if you don't ask you're not going to receive. It's the mentality that you think that, as a parent with a child with a disability, you are imposing if you ask for help. You never get the impression that it's your right to get the service, just as we have a right to food or we have a right to a certain level of social comforts; we don't think that we have a right to be taken care of by the community. We have to ask, and we feel very guilty because we like to take care of our kids, we don't like to say, "Hey, I need a hand here."

MS SCOTT: I see. Thank you. Could you talk about the number of organisations you have to then interact with in order to care for your daughter? Is it five organisations? Two? 10?

MR MONTEAGLE: We have Scope at the moment. As I said, we're going through Baptcare, we're going through a day care centre, the name of which escapes me. That's based in Keilor. I can provide you with the details, if the commission needs it. We are using Spot 4 Kids for private therapy and we have just recently engaged a private psychologist, who is doing the autism assessment. The psychologist has told us we will probably need to get a qualified speech OT, maybe even another paediatrician, to give us the autism assessment. Once again, based on their qualifications, we may need to fund that ourselves, we may not.

The autism gamut, or gauntlet, we're just figuring it out, and you get sent round and round in circles, with the GP telling you you've got to go to this mob, you speak to Scope. At the end of the day, like I said, I had to just pick up the phone. I called Autism Victoria, and after a few different phone calls, once again, people don't call you because they're very busy, you finally figure out a vector of attack and you pursue it. But you shouldn't have to be that pushy.

MS SCOTT: In terms of your other responsibilities, how much time, when you first came back to Victoria, would this have absorbed of your day, to make sure that all the services were connecting and that you were aware of the right services, that you were asking for the services that are available?

MR MONTEAGLE: Me, personally?

MS SCOTT: Yes.

MR MONTEAGLE: It would have been half a day to a day a week, which is an interesting point, because although it's not about me, I 'm a contractor, so if I take time out of work to be here I'm not getting paid. So, yes, there's a financial impact there as well. But, yes, first it would have been half a day to a day a week. At the moment, as I said, my wife struggled with the autism maze for a month and couldn't get anywhere, because she's a busy woman. So now I make phone calls during the day and I'm trying to chase that up. So that would even be about an hour to a couple of hours a week now, when things are supposedly stable.

MS SCOTT: Do you have any control over the funding available to your daughter?

MR MONTEAGLE: You do to a point. The funding, insofar as day care or therapy, it's an interesting trade-off. We were discussing last night about this additional funding for Spots and what we should do with it, because we at the moment have one visit every two to three weeks, we could get another visit but we'd have to give up the day care. My daughter goes to day care once a week for about four or five hours, and that's therapeutic in itself because it's her only opportunity to see other kids and to watch them interact and that's very helpful. So we decided that we can't lose that, we have to keep that in place and fund additional therapy ourselves. It's basically just not enough.

MR KALISCH: So would you welcome having more funding but the ability to choose how you used it?

MR MONTEAGLE: Yes, without question. I noticed that in the discussion paper it said we have got to be careful that people don't drink it all or gamble it; but that's fairly easy to police, in my opinion. Even if it's a case of, okay, I've got X number of dollars to spend this year on my daughter, obviously I don't get the cash, I have to put in my preferences. I mean, we're on the waiting list for a heart walker for my daughter, it's going to take at least six months of Lions community fundraising, she should have that now, extra therapy, as I said, autism, things like that. So we are given sufficient control over our daughter's needs, it's just that there isn't enough of it there to meet the standard, and you feel guilty, you feel greedy when you're asking for more, even though there's a legitimate need for it.

MS SCOTT: Do people remind you about other relative needs relative to your daughter?

MR MONTEAGLE: No, they don't. We really have to do this ourselves. As I said, we have to be proactive. The whole autism thing that has come about fairly recently, because my daughter had the hemispherectomy, so it took six months for her to really rebaseline, and now we're looking at her again, saying, "No, there's these areas here that we need to focus on." So we will prompt that with the community worker and then they will point us in the direction of where we have to go. So, yes, it does come back to that overall service level of care that we really want to see beefed up, and we really want to see that it's held accountable so people do feel like there's an obligation there. If I'm a care worker and you've got a disabled child, it's my job to look after you, and if I'm not doing it then questions need to be asked.

MR KALISCH: Is part of the challenge actually getting information about what care options are available?

MR MONTEAGLE: Yes.

MR KALISCH: Has the Internet provided a source of information or is there a differential, in terms of its quality?

MR MONTEAGLE: It's funny you should say that, because I actually diagnosed my daughter over the Internet one terrifying morning. So the Internet can be a scary place when you've got a disability. With time, we have learnt how to use it objectively. The Internet if very helpful, yes. As I said, with the recent autism adventure, we got a lot of information off the Autism Victoria web site. But you're probably going into a whole other issue there, because, professionally, I have a lot of experience with the Internet and technology systems, and, unless the Internet is managed correctly, there's almost as much irrelevant information as there is relevant information out there.

For someone like my wife, who isn't Internet savvy, who don't know how to pull the right information off the Internet - I'm thinking of people like her, and other people I know, housewives - without sounding condescending - that don't have the experience and the skill-set to pull information off the Internet and assess it objectively. They need to have someone to come in and guide them through that and take care of it for them.

MS SCOTT: Are you familiar with the Transport Accident Commission model here in Victoria, in terms of lifetime care?

MR MONTEAGLE: Yes.

MS SCOTT: The report that, in some ways, led to the Productivity Commission getting this reference, the Disability Investment Group Report, recommended a sort of a no-fault lifetime care model, based, in some ways, on either the New Zealand scheme, the Tasmanian scheme, the Victorian scheme or a new scheme in New South Wales. Those schemes do have a central funder, but they then use outsource services to provide care. I just note in your submission that, while you want one body, you're concerned that carer facing roles should not be outsourced to a third party. Could you just talk about why you are worried about outsourcing? Is that reflecting your experience, or something that happened in Queensland? Could you just talk about that?

MR MONTEAGLE: It's reflecting my experience, to which I was alluding earlier. Look, outsourcing per se isn't a bad thing, providing the accountability is there. My concern with outsourcing is that if you start to fragment the services, then you're back to where you started, with me having to make half a dozen phone calls if I want autism, if I want cerebral palsy. So if you outsourced a central point of contact close to the community, that would work, in my opinion. But if you started to outsource those disparate services around the community, that's not going to help. Does that make sense?

MS SCOTT: Yes, that's fine.

MR KALISCH: Yes, no, that's fine. That was one of the questions I had as well. Just taking this slightly further, so if it was the responsibility of the managing organisation to deliver services - whether they be from one, two, three or four service providers - that would be then effective for your needs, as long as it was managed properly and they came when they did and they did what they needed to do?

MR MONTEAGLE: That's right. I suppose the only other caveat I would put on that is if there was equity between the different areas. So, once again, I highlighted the problems with zones in Melbourne. So as long as they're provided in the same level of service, then that would suit my needs, yes.

MR KALISCH: Because, obviously, in your situation, and many others, it's not just a single disability that needs to be addressed.

MR MONTEAGLE: No.

MR KALISCH: I mean, there are often comorbidities and other dimensions navigating the health and other disabilities.

MR MONTEAGLE: That's right. I mean, we're dealing with autism; we're dealing with cerebral palsy; we were dealing with epilepsy up until late last year. So, yes, it's a mixed bag.

MR KALISCH: Thank you.

MS SCOTT: Chris, thank you very much for your submission. We don't have any further questions. Thank you.

MR MONTEAGLE: Thank you very much.

MR KALISCH: Thank you.

MS SCOTT: We'll now call forward Tony Tregale. Yes, thank you, Tony. Would you like to make an opening statement?

MR TREGALE (LISA): I can do, yes.

MS SCOTT: Welcome, Tony.

MR TREGALE (LISA): Thank you.

MS SCOTT: Please, if you could just identify yourself for the recording and indicate if you're representing a group or an individual.

MR TREGALE (LISA): In respect to this hearing I, Tony Tregale, represent Tony and Heather Tregale as very caring parents, plenary guardians and administrators and as the coordinator of LISA, Lifestyle in Supported Accommodation group.

MS SCOTT: Thank you. Would you like to make an open statement now, thanks?

MR TREGALE (LISA): Well, I'd just like to say, unlike the previous speaker, it's totally different. We are from a different end of the spectrum to the previous speaker. We had a lot of empathy for the previous speaker and I'm not sure we can be as articulate. However, we have two sons. Our eldest, 39, is a corporate business manager, married with two children. Our youngest, Paul, is 34, is autistic and has very limited intellectual ability. Paul lived at home until he was 20, when we reluctantly decided we were getting no younger to provide 24/7 care, sick, and might depart this world at any time. Since this time Paul has lived in a DHS supported accommodation group home in the community 10 kilometres from us. He is with us for a day each week, at least a day each week, and my wife Heather visits him once a week.

Our extensive experience of disability services is from providing extensive behaviour management and direct care for Paul, which the previous speaker was talking about but with a four-year-old; being community visitors for six years; and Heather having worked in group homes for four years; and negotiating quality of care for Paul with DHS and assisting other families. So our experience comes from that. Our very longstanding findings are that the current system of support for people with a disability and their families is deeply flawed, with much of the service provision providing little more than basic minder care. I think mum and the little one - she worries about the little one at kinder where often they will - "Are they doing anything with the little one?" But the little one can probably come home and tell mum, "Hey, I did this or I didn't do this," but the 34-year-old with no speech, mum worries even more.

So in many cases we find that as a direct result - it is the direct result of captive market service provision attitude rather than resources. Though most of our focus is on the Victorian government direct care service provision we are concerned this government, through DHS, is unable to provide effective and meaningful scrutiny of non-government services it is funding. I think that's what the previous speaker was talking about - accountability. Some of our key points are: government direct care services for people with a disability are run by captive market public servants who have little reason for customers or customer services. These services are like Telecom before Telstra, and if you remember that, it was pretty horrible. I believe again that's what the previous speaker was saying, they want some accountability of service, and we're finding there is not in the government direct services. I have a large number of points here but I think I might pass it over to you to - - -

MS SCOTT: Okay, that's good. Could you tell us what Paul's day is like now?

MR TREGALE (LISA): He has a day placement which we are concerned about in the sense of it being more of minder care than quality of life care. In respect of quality of life care we mean doing things with them rather than them sitting looking at four walls. All of us here today have an intellectual ability avenue as large as a city block. We say we have so much ability we don't have the time in a day to use it. If you have an intellectual disability it is the complete reverse.

MS SCOTT: So he has day placement. Could you talk about the other care that he might receive during the day?

MR TREGALE (LISA): Well, that is his basic care during the day. In the evenings, again we're concerned that it's mostly minder care rather than activities such as going to the spa, going out for a meal, bowling - activities, they really need activities. They need to be encouraged to do activities because - the other speaker mentioned autism. The best thing that people with autism do - we're talking low-functioning autism, not Aspergers. Low-functioning autism, the best they do is nothing unless they are encouraged to do something meaningful.

MS SCOTT: Are you aware of how many activities he would do in a week that would actually stimulate him or that he would enjoy? Are you conscious of the activities that he would do? I mean, are you aware of a program of activities that he would have?

MR TREGALE (LISA): We are. Yes, we are aware.

MS SCOTT: What would your view of those level of activities be in terms of their variety or - - -

MR TREGALE (LISA): We would say they were low, limited in variety.

MS SCOTT: How would you describe his life and his level of enjoyment?

MR TREGALE (LISA): It fluctuates but it's mainly low.

MS SCOTT: Thank you.

MR TREGALE (LISA): I mean, when he's with us - for example, at the weekend he's quite often with us on a Sunday. Almost every Sunday we have him for the day and we specifically try to make up for what they don't do and he does things like help to put out the washing, carry the washing basket out and put out the washing, put the recycle things in the recycle bin and generally help around the - empty the dishwasher and these sort of things. But unless we actually encourage him to do that he will be around doing nothing. So it's very easy for people with autism to do nothing.

MS SCOTT: One of your key points is the idea that it's a captive market for services and that the providers treat you as a captive market rather than inadequate funding. Could you elaborate a bit more on that? I mean, what examples can you point to of this captive market element?

MR TREGALE (LISA): Well, the captive market, they have no - the previous speaker said they don't come to us. We have to bang on their door, they don't come to us. Now, if you're a business in the community - I mean, a good business in a community - the business wants to retain its customers. It wants to do everything to please the customer. Government direct services do not really care. I mean, if you have a deal with Myer or David Jones and it's not a good deal you tell all your friends. You get on email and you tell all your friends what a rotten deal you just got. So they try not to let that happen. The manager will call you up, "Let's have a cup of coffee. Let us talk." You're not encouraged to go there. Does that answer your question?

MR KALISCH: Yes, no, that answers it very well.

MS SCOTT: In your submission you are critical of the complaints process and you said also in your opening remarks that effectively there's no accountability at all. Would you like to explain, given your years of experience, where you think things are at the moment, why you feel that there's no effective accountability.

MR TREGALE (LISA): There's no effective complaints system here in Victoria. Parents usually finally give up, because there isn't. There's nowhere to take your complaint where something will be done, and again I talk about the DHS, but not-for-profit also takes funding from the DHS. But if we just keep the DHS direct care, there is no accountability for what they do, because the only person who can direct the Department of Human Services to do anything is the minister, and generally the minister will not do anything, because it would politically give the opposition ammunition if they're complaining about their department.

So the only person that can direct the complaints process in Victoria at the moment is the ODSC, Office of Disability Services Commissioner, and they are very weak, all they can do is conciliation, they're very weak, they have no power over the department except to make recommendations. So if you have problems with any part of the service it's extremely difficult to get anything done, and usually parents just give up and go away. That's exactly what we find that they want to happen, they want that to happen, "Go away. Don't tell us. We don't want to know," whereas a company in the marketplace would say, like a restaurant, they'd put a notice on the table, "We want to know what our service is like. Please tell us if you're not happy." The department never tells you that, it puts every possible thing in the way of you making a complaint.

MS SCOTT: Have you ever been surveyed about the level of services that your son is receiving? Have you ever been asked for your feedback?

MR TREGALE (LISA): They do a general survey, it's very general. Very general questions.

MS SCOTT: Thank you.

MR KALISCH: So do you have a good understanding of the way in which other accommodation is provided? You have obviously got intimate knowledge of the accommodation that Paul is in. Are you aware of other homes and whether they're run better or worse?

MR TREGALE (LISA): We have some knowledge of the not-for-profit services, the community services organisations. We are a member of NDS, National Disability Services. We do see some of theirs. We feel there is more accountability in the not-for-profit services than there is in the department. In fact, those who remember Jeff Kennett, whatever you might think of Kennett, Kennett did try and get the department out of direct service provision and move it all over to the not-for-profit services, but he didn't succeed because of the pay differences between workers.

There is a lot of complaints about the not-for-profit services as well, but we feel there is more potential for accountability there, because if the department funds the not-for-profit services then they can say, "You are not running your service within our standards. So if you don't do something about it, we will pull the funding on you and we will give your services to some other service provider," whereas, with the department, they never put pressure on their direct care services to provide service within these standards.

MR KALISCH: So you are suggesting that there is a role for the department, in terms of sort of standard-setting and monitoring and accountability?

MR TREGALE (LISA): Yes.

MR KALISCH: And that that may then directly conflict with also their role as a service provider?

MR TREGALE (LISA): Yes, we believe it does conflict with their role.

MS SCOTT: Thank you very much, Tony, for your submission and for your presence today.

MR KALISCH: Thank you.

MR TREGALE (LISA): Thank you.

MS SCOTT: Welcome Valarie, to our hearings today. For the record, could you identify yourself and indicate whether you're representing yourself or a group?

MS JOHNSTONE: Yes, my name is Valarie Johnstone and I am here representing myself and my experience of disability services, from a professional point of view and from a personal point of view, and being a parent of a young person who has a disability as well.

MS SCOTT: Thank you. Would you like to make some opening comments, to lead off?

MS JOHNSTONE: I guess I wanted to make two key points: one is about consistency and the other one was about special disability trusts. But in so saying that, when I talk about consistency it's about the points that were picked up in the issues paper about the discrepancy of some people who have huge packages, or what seems to be huge packages, and some people who have pretty much nothing, the discrepancy as picked up in the paper, like in my experience as a social worker, what I call the Rolls Royce version, when someone has a traffic accident or a Workcare accident and someone who has fallen off a cliff, or whatever, you know, so me working in rehab in one setting and working in rehab in another setting, two totally different experiences to see what people actually receive.

Also, inconsistency, it's not about just who receives something, it's also about picking up that point about aids and equipment, about consistency, there looking to how specific aids and equipment could actually enhance the lives and the quality and early intervention of a range of disabilities. It's not just as simple as saying, Oh, yes, this person needs a wheelchair," it could be a range of things. The other one is allied health, and that comes into early intervention and consistency. The points that our previous speakers have made about you always having to ask, the person always having to identify and be proactive. What about people who don't understand?

I'm sort of getting away with myself. I should have said, I have a vision impairment; and I have a daughter who has Down syndrome, who is fantastic. But basically that comes back to the stuff that I was saying before about people actually understanding the system and working through that and being proactive and picking up that early intervention stuff. So in a sense very early in the piece I said, "No, this is not for us," and I just pretty much followed my own path, which then has led us in a very different trajectory and we have achieved a very different outcome to what has happened in other circumstances.

So in relation to special disability trust, it was very interesting. A couple of years ago I was doing some estate planning and this whole thing of special disability trust came. I was made aware of it, and I said, "Oh, that's a great thing." So I said, "Oh, well, I'll look into it," and when I rang the unit in WA they said, "Oh, you're not on a carer's allowance." I said, "No, I'm not." I know there are whole arguments about it, but, in my opinion, and this is just my belief, if I've got two children, well, I'm a mum to two children, I can't be a mum to one and a carer for the other, and different children have different needs and different expectations and things like that.

Anyway, they sent me the form, because that was the process. But that form is basically based - and I have brought a copy of that, so in the break I can even show people - it is based on the dependency. So when I was filling in the form, or had to take it to the health professional, I had to say, "no", "no", "no", "no", "no". So obviously, when we submitted the application here was Fiona, who has Down syndrome, living in the community in a unit that I had purchased, and all we were looking for is to put that unit in a special disability trust so she had tenure and a roof over her head and all of that, and we were knocked back, basically because she was too independent. Have you ever heard of the stupidity of that?

So the people I spoke to in WA said, "Oh, yes, we understand what you're saying," and blah blah blah, and, "Put it in the senate review" - there was a senate review into special disability. So I did that, and actually the points that I made have been picked up in the recommendations and things like that. But the point is, people say "intellectual disability," but, to be very honest with you, I think people have been sold a pup. It's about understanding the difference of, yes, you have a diagnosis; yes, there is a functionality; and then there is environment. There are three components. So it's not just about diagnosis, it's about the degree of functionality and how that's applied, and the environment that actually enhances or detracts from that.

So I, for one, would certainly be saying that when we are looking at special disability trust it's about looking at all the stakeholders in someone's life. Yes, there might be state, Commonwealth, federal responsibility, but there is a family responsibility as well and there is a community responsibility. When I say "state", I mean, you know, the Commonwealth too, public. It's about facilitating a process and ensuring quality and standards and things like that. Families can contribute in all sorts of ways, just like how we contribute to the lives of our other children, everybody's children.

But also, when I talk about community, some years ago I did a paper called Enabling Citizenship, and basically the point I was making in that paper was that people become attached to place and community only by a social exchange. So if you go to the shops, if you go to the bank, if you go to your podiatry, or whatever, it's building that social exchange. If there's always someone else in between as a buffer, always someone else in between, there isn't that direct social exchange and you're not then developing a relationship with this other person.

So when I say Fiona is fantastic, she lives on her own and she has done so for the last - February will make 13 years, so we are moving on to our 14th year now.

We have been on direct payments right from the word go; so in the pilot and continuing on now, it is fantastic. So we basically purchase the bits and pieces that she wants, and, whilst it's in her plan and we have budgeted for seven-and-a-half hours a week, she only uses two and a half.

MS SCOTT: Can we just pause there for a second, Valarie. I just want to go back to some of the points, if that's all right, to explore them a bit further. So you've identified two issues that I'd like to explore.

MS JOHNSTONE: Inconsistency.

MS SCOTT: Inconsistency. We have had a bit of theme about inconsistency this morning. Then the specialised disability trust. But I might just go on to inconsistency at the moment. Does the inconsistency arise, as you said in the issues paper, from the source of the funds - so someone who gets assistance from the Transport Accident Commission versus someone who gets assistance from DHS - or are you seeing inequities across individuals from the same source of funds?

MS JOHNSTONE: Both.

MS SCOTT: All right. Thank you.

MS JOHNSTONE: So, like, for instance, you would see people with ABI or people who don't have much family in a rooming house or in a special accomm, and you know darn well that they shouldn't be there. Or there are some people who might be in a CRU, who don't have much family, and I bang on about this, about transition; they know that, yes, there is individual funding, which is what all the documents say, but they haven't been afforded the facility of saying, "Let's try this. Let's do some transition modelling and see whether you like or not." There isn't an enabling policy or an enabling approach rather than, "Well, if you go down that way, well, you've burnt all your boats." Of course people want to deal with the devil they know rather than the devil they don't know.

MS SCOTT: I understand. Can I just go back now to your experience as a mother, with Fiona. You were saying that her experience is quite different from others maybe in relatively similar circumstances; she lives independently. Was that something that people had anticipated that she would be able to do or was that something that she thought she could do and you thought she could do - - -

MS JOHNSTONE: It was our approach.

MS SCOTT: Were you a social worker before you had Fiona? I mean, I'm trying to work out how much of Fiona's success we can put down to particular interventions or the system naturally operating to - - -

MS JOHNSTONE: No, it's not the system. I will give you three examples. Reading, "She'd never be able to read."

MS SCOTT: They told you that?

MS JOHNSTONE: Absolutely. Well, I rolled my eyes and said, "Well, I don't accept that," because I could see reading, even if you looked at functional reading, was a must for anyone to sort of move on. So we started with that. But pretty much she's a very good reader. She spells, she writes. Even if you think of the way we develop, it's all about being engaged very early in the piece, it's the same.

The second one was transport, travelling on public transport. Now, it was about modelling and it's a good thing that, in a way, I have to depend on public transport. So even when my husband was alive, I would say, "No, Fiona's life is public transport. It's not about hopping in the car and taking her down the street. If she's going to be independent, her life is public transport. So she needs to get confidence in that and she needs a good, strong role model in that." But now, the places that she goes to, she's pretty good. So that's the second one.

The other one was about the social interaction and the social exchange. It was about understanding that dynamic very clearly. If you always are a mouthpiece or you have someone else being that buffer, the person then doesn't engage or doesn't have that opportunity. It's very interesting, because talking is not her strongest communication form, she's better at writing things - and it's very interesting that she worked out for herself - so when she goes to the movies, when she has to buy her Met ticket, she will actually write it down. So that the person - because one day I went to the milk bar and the woman said, "Oh, Fiona's Met ticket hasn't come in again." I said, "Well, what are you talking about?" "Oh, she was her this morning," and I said, "Oh, I didn't realise that." You know, so - and I said, "Well, how did you know?" and she says, "Oh, she has it all written down." I said, "Oh, okay."

So that's what I'm saying. It's about - I mean, sure, the first couple of times the person might say, "Oh," you know, and sort of wonder why is this person handing me this piece of paper but after a while that person understands that this person is a customer, as one of our other speakers said. This person is a customer and there are different ways of communicating.

MS SCOTT: If reading, using public transport, the social exchanges were key to her success, if she had been left just to get on, as other people were going to advise you, what do you think her life would be now?

MS JOHNSTONE: I can't imagine. That's why I've been determined to come here because it break - I do a lot of work in disability, I'm with the department and things and I always used to say it's about giving opportunity, it's about creating opportunity, it's about being - you know, that whole early intervention thing. It's about looking at, well, what are the barriers, what are the opportunities, encouraging parents. Because the way I see it the rewards are in the wrong place, and I will do a detailed submission and put it in. But the rewards are in the wrong place. It's about demystifying and it's about, you know, giving people the support like our first speaker - young families. I mean, I know lots and lots of people with disabilities, lots and lots of families. It's very interesting to see different people's approaches. But of course young families need that assistance to demystify, they need the assistance to, you know - yes, to give them that full-on physio, OT, whatever.

MS SCOTT: We look forward to getting your submission but you said rewards are in the wrong place. Could you just briefly talk about that for a minute or two.

MS JOHNSTONE: Well, use the whole carer thing - I mean, and please don't think I'm banging on about carers. It's just an unfortunate thing as far as I'm concerned. But just look, that's rewarding dependence; it's not rewarding - like, you know, it should be turned around. You know, I mean it just doesn't make any sense to me at all.

MR KALISCH: You talked about aids and equipment and I'm just sort of wondering about your experience of that in Victoria.

MS JOHNSTONE: Well, from a person with a vision impairment point of view our equipment, as anyone would know, is frightfully expensive. It's all very well for someone who is in paid employment, you get it through some sort of workplace modification, all of those sort of things. But there's a very small percentage of people who are meaningfully employed and gainfully employed. So what about all the people who aren't employed, and then to have access to that very expensive equipment? So that's just one thing. But even to do with cognitive disability it's about exploring what are the other things that are available. It's not just about high-tech equipment which has recently been part of a small work group at DHS where I was making the point, it's about low-tech stuff because I see with Fiona, because it's to do with the thinking, it's to do with giving her control and things like that - just things like a planner, a pin-board - you know, things that give her control but actually are helping her to look and plan and, you know, those sorts of things; so aids and equipment across the board.

MR KALISCH: Can you just give us, I suppose, a bit of a sense of what it's like to navigate through the public system to get aids and equipment.

MS JOHNSTONE: It's dreadful.

MR KALISCH: So are there multiple providers or - - -

MS JOHNSTONE: The bureaucracy, sometimes you wonder whether the bureaucracy is there to not get you something as opposed to enabling - and you wonder about the cost of that. Surely that could be simplified as, say, this is my - remembering the three parts that I made earlier about disability, functionality - - -

MR KALISCH: Functioning and environment.

MS JOHNSTONE: If you're clearly putting something saying, "This is my situation. This is how I think this is going to assist me," you know, "This is how I see the short-term, long-term benefits," I mean, that should be a paper exercise, even if it's a question of saying, given my first point about being consistent, which means equity as well - even if there's a question of saying there's a dollar figure or some sort of a number, but at least people then can work towards that and say, "Oh, well, I've got $2000 towards something that's going to cost me $5000." But, you know, at least there is something there rather than nothing, but also you don't have to go through this absolutely demoralising thing. Yes, it's not very good.

MR KALISCH: I suppose one of the aspects that you noted earlier was the consistency and Patricia has asked you a few questions on that. I mean, is there also - I suppose I just wanted your perspective, probably more from your professional life, as to whether people in some of the more expansive and more generous schemes actually receive the opportunity for more services than they actually need or is it tailored to their need?

MS JOHNSTONE: You mean like TAC and WorkCare?

MR KALISCH: Yes.

MS JOHNSTONE: Definitely there's more scope, definitely far more scope and far more movement - it's not rigid - and in fact that model has been used in relation to direct payments.

MR KALISCH: So you see some benefits in moving toward that type of model more broadly?

MS JOHNSTONE: Direct payments?

MR KALISCH: Yes.

MS JOHNSTONE: Absolutely. The thing is, what makes me cross is that people don't know about it. Like some of our speakers say, "Oh, we can't move," but actually you can. But you can understand why the service providers, it's not in their interest to tell you that, but you actually can. But that point about being captured, I was nodding my head. I said, "Absolutely," because people are terrified. They say, "Oh, yes, we can," but they are scared, you know. So a lot of stuff has to be done about - it's an old-fashioned word - empowering, but giving information, enabling people to actually make those choices. But also the other lever is demanding or putting a few more pressures on service providers. They talk about independent monitoring in Victoria, they talk about quality of care frameworks, but one wonders.

MS SCOTT: Can I go back to Fiona's circumstances and your interest in the Disability Trust. You've indicated that she's living independently but she also has some cognitive disability.

MS JOHNSTONE: Absolutely. She has Down syndrome.

MS SCOTT: Down syndrome.

MS JOHNSTONE: It's not going to go away.

MS SCOTT: No, I've got that. So not putting too many sensitivities on it, but I mean - - -

MS JOHNSTONE: No, no.

MS SCOTT: - - - what is going to happen over her lifetime, after you die? Could you comment on that? You're obviously thinking forward.

MS JOHNSTONE: Yes.

MS SCOTT: What's the arrangements that - - -

MS JOHNSTONE: Well, at this point in time, because we got knocked back with Special Disability Trust, which I'm not giving up on, I guess in the interim it's about, like, testamentary trusts or something like that, but I envisage Fiona's unit to be in a Special Disability Trust. I've got an investment bond in her name sitting in my super which then covers if something happens to the unit or whatever. She has her package, which is recurrent, which buys her support things. To be very frank with you, I was recently quite sick and she was fine. I don't know why I was even mentioning it to my doctor. I said out of all the badness out of not being well, the good thing was that Fiona was actually fine. Yes, there's that emotional tug and what I said was that we just talk on the phone and things like that. But on a practical level, well, I was obsolete. But actually whilst you understand there will be that emotional stuff which she will go through, like anybody, on a practical level, she will be fine.

MS SCOTT: And there will be a custodian or - - -

MS JOHNSTONE: These days, I think even in Victoria there are going to be lots of changes to do with the Guardianship and Administration Act, so these days they're looking at circles of support, and Fiona has got a good circle of good strong family friendships and nice strong young women around here, so I would be looking at that, rather than a formal guardian which was the old model, to actually have a circle of support and maybe someone who's got some good bookkeeping skills or maybe purchasing some bookkeeping skills to do her admin stuff.

MS SCOTT: What level of support is she receiving from the Victorian government now? Does somebody drop in? Is she entirely independent of them?

MS JOHNSTONE: Are you asking about her direct payments package?

MS SCOTT: Yes, I am.

MS JOHNSTONE: Okay. So the direct payments package, the way it works is you get a letter saying, "This is your recurrent funding," and they work that out. It goes up with CPI and things like that. We then put in a plan which you're encouraged to make as broad as possible, so then the strategies become quite fluid and flexible. So we've got her direct care hours, we've got what we call time out which is "respite" and then we've got her out and about which is the stuff that she does, just participating in the community.

MS SCOTT: Yes.

MS JOHNSTONE: So we've got broad sort of headings, but that then gives her a lot of flexibility.

MS SCOTT: Does she have the skills and the confidence to be able to make those decisions herself or is that something she has to be guided in?

MS JOHNSTONE: It's very interesting - and I've still got that at home, it's so special to me - but when this was first mooted, we sat down and we did it on pieces of paper and she has written it in pencil and it's like, "Things that I need help with, things that I need someone else to do for me and things that mum needs." That was just the starting point. We've had to revise that from time to time, because it's really interesting to see, if you use that as a measure of how she has actually grown, doing stuff. It's really good to say, "She can actually do lots and lots of stuff," so it's actually a very good exercise. But, yes, she does need guidance. To give you an example with the out and about, we look at all the brochures, she'll look at it first and she'll say, "I like that, I want it," and then I say, "Go back to it."

The point that I always make with the department or anyone, especially for people with cognitive disabilities, the thing that you need most is time. You can't say, "That's the first thing they said," or, "They said that." No, you've got to go back, check; go back, go through it, and you need the time to actually know that that is what they wanted and it's in their interests, not just the first thing, because what I always say, "Look at your bankbook, have you got enough money?" because she needs to understand - because as I said, as far as I'm concerned, she's living in the real world. She has to understand those things.

MS SCOTT: Thank you very much.

MR KALISCH: Thank you very much.

MS SCOTT: We are going to have morning tea now, so if you'd like to have a cup of tea and a biscuit outside, please join us. Thank you.

MS SCOTT: Good morning again and welcome back to our hearings. We've now been joined by John Walsh, our associate commissioner from Sydney, so welcome, John.

MR WALSH: Yes, good morning, everyone.

MS SCOTT: I now call forward Cath McNamara and Sue Whiting, please. Welcome. Would you like to make an opening statement?

MS McNAMARA (AFCL): Just to introduce ourselves, I'm Cath McNamara, systemic advocate, and Sue Whiting, who's a board member, and we're representing Action For Community Living which is a disability advocacy organisation. We will be making a written submission but we wanted to make particular points today. Number 1, we believe very strongly and have argued for a long while that entitlement is an essential part of upholding people's rights. Having ratified the UN convention, I believe that Australia really has an obligation to ensure that people with disabilities who require support to have a quality of life that's commensurate with others in the community have access to that support. While we recognise that their governments have finite resources, it's really unacceptable that people with disabilities in Australia are without even basic supports and go on waiting lists to get out of bed in a dignified way in the morning or to get their legs or their voice through equipment.

The sorts of supports that should be funded are the additional things that people need and this may be physical support or cognitive support or behavioural support. It may be aids and equipment. It may be home and vehicle modifications and may be things like assistance to set up and manage their supports. We really strongly believe that Australia has an obligation to fund these additional supports and aids to cover the real costs, not at the minimal whatever we can get away with, the cheapest version. While Sue and I are talking about this, Sue will be using a light writer when she talks, and it's the basic model. Unlike some people, if they have access to more expensive equipment where the voice just comes out in a whole sentence, Sue's will come out word by word and a bit laboriously, so that consistency again about the two-tiered models.

In terms of eligibility, we believe that the scheme should be available to all people who are born with or acquire a disability who have ongoing additional needs related to their disability and regardless of the cause of that disability. We recognise that initially the scheme may need to be restricted to those who acquire their disability before the age of 65 but in the long term, we prefer to see that any people who have disability-related needs, regardless of their age, should have access to the support and equipment that they need and that operating a two-tiered system where you have people who are over 65 in one scheme and people with exactly the same needs who are under 65 in another scheme doesn't seem to make sense. Sue, do you want to say something about how long it should last? It's taking a while to get going. It's the basic model.

MS SCOTT: What sort of cost difference would there be between a basic model and a better model?

MS McNAMARA (AFCL): Sue, do you know the answer to that, the difference to one like - in terms of cost? Several thousand dollars. The machine actually cut off the beginning of that, and particularly as it comes out word by word so slowly, we thought it would be better if I also read it again. What Sue was saying was that, "A long-term scheme would be a vital tool for all people with disabilities and people with high-support needs such as mine. Like many people with disabilities, I have contributed to the wider community, either in an employed or a voluntary role. I would like to have the opportunity to have the support that I need to continue my lifestyle as I wish. A long-term scheme must mean exactly that and continue beyond the age of 65. Each package can't be the same as we are all individuals and our needs change due to age, interests, relationships with family and friends."

The other point around eligibility was that we believe that the scheme should not be means tested. While recognising that that might mean that some people who are millionaires might get the scheme, the disincentives inherent for workforce participation for the majority of people with disabilities, inherent in a means-tested scheme, we believe, would fair outweigh any savings that might be made by the means testing.

In terms of assessment, we believe that the assessment system must allow for the complexity of people's lives. Traditionally, assessments have been inflexible to tools that compartmentalise people's lives and we believe that this should be a much more holistic process that looks at all aspects of life and takes account of the person's strengths and capacities, like Val was talking about, as well as their needs. Needs should be looked at in the context of the person's aspirations and goals.

That assessment process should be assisted by someone who's aware of the eligibility and funding issues but independent of both the funders and the service providers. One of the things that we've seen with, for instance, the TAC model, when the assessors are employed by the funder, they're under a lot of pressure to minimise and to limit the amount of cost involved in somebody's support, so we believe that there should be some independence.

They also need an extensive knowledge of disability and its impacts and it shouldn't just be a medical process or just clinical. It's very much about that whole-of-life sort of approach. The other thing that we're seeing in the current system is that sort of competitive misery approach, where people are kind of put in the terrible position of having to emphasise how dreadful their life is to try and convince the funders that the rationed support should go to them rather than to somebody else and that seems an appalling system in a wealthy country.

The other point we believe is important and Val talked about this too, there needs to be flexibility. The discrete programs that we see at the moment, where every program has their own eligibility criteria and you're having to work your way through this maze of different funding bodies and whatever just adds to the complexity and puts up barriers, and that an individualised approach with that sort of flexibility around people deciding, within agreed parameters, how their needs can best be met, is the way that will support people having a quality of life.

In terms of power and decision-making, we very strongly support the idea that people with disabilities, with the assistance of supporters if necessary or desired, should have control over how their funding is used. I will read this - I'm Sue for a minute - "As a person with a disability, I strongly believe people with disabilities must be given the opportunity to direct where their funding package is spent. I need to be given the power of choosing the services that I need to be able to keep my lifestyle as I wish. Decisions must be made by me as I am the only person who knows my lifestyle. I may not wish to employ my own support workers directly because of the responsibilities this involves or if I choose to employ my own support workers, I would have to have the resources and training to allow me to go in this direction."

Val has talked about the experience in Victoria of direct payments and I think people who are using that model are finding that it gives them a degree of flexibility and control that a lot of people would want to support their lifestyle. But if people choose not to do that, there should be a range of options, either going through a service provider or having a financial intermediary.

The final point we want to make is that as well as the individualised approach, we believe that there needs to be sort of infrastructure surrounding that to make sure that vulnerable people are protected and that people get the advice and information that they need. So the sort of thing that we would like to see is community living centres or independent living centres along the lines of the models in Canada or Berkeley in the United States where it all started. People with disabilities are employed there and are available to provide advice and information to assist people to manage their funds and their support, and they can provide information and referral, peer support, independent living skills training and other services, possibly administration of funding.

The other thing we believe is needed is some resourcing for community development and capacity building. There needs to be people who are working in the community to open up the general opportunities for people with disabilities and to resource the community in knowing how to make sure that they provide better access and better support for people with disabilities in general community services and activities. The other thing that we believe is needed is independent advocacy support for people with disabilities who may need assistance to access the system and who may need assistance to have their voice about the things that might be concerning them about the way things are running or whatever. We believe this should sit outside the package system so that people are not required to buy that out of their package.

MS SCOTT: Thank you. John, would you like to lead off on questions.

MR WALSH: Thanks very much Cath and Sue. I'm interested in you mentioning the independent living centre idea, Cath, from Berkeley and Canada. There is an independent living centre in Sydney where I live and I think in other parts of Australia. They're predominantly equipment and advice services. Could you talk a little bit more about how independent living centres in Berkeley and Canada operate?

MS McNAMARA (AFCL):   The centres are actually run by people with disabilities, and there are people with disabilities employed there and they're providing a much wider range of services. Yes, our independent living centre here, John, is exactly as you're describing. It's basically equipment and advice about equipment. This is much broader and it's about assisting people to gain skills so they might be able to run training programs. Our organisation at the moment is in the throes of developing such a training program where people with disabilities learn about how to manage funding, how to be an employer, how to direct their support workers, those kinds of things. So if they have had no experience in that before they can learn those skills. They can come and hear from other people with disabilities who have been doing it a bit longer than they have, get advice and assistance to do that. That could be available to people with disabilities themselves and their family members if they're supporting someone with a cognitive disability.

MR WALSH: Are the centres also used to help potential workers in the field of disabilities? Obviously we've got a big issue with workforce in disability and the certificates for attendant carers are very good, but maybe there's something lacking there in understanding what a disability is like. Is that something that the independent living centres do as well?

MS McNAMARA (AFCL):   From the quick research I've been doing I'm not sure, but I certainly see that as something they could be doing and we could look at. There's no need to slavishly follow what happens elsewhere. I agree with you that certainly one of the other issues that our organisation has worked on a lot is the workforce issue and often the attitudes of people who work with people with disabilities. There's need for both improvement in that and upskilling people and particularly assisting people who are working with people with disabilities to understand that they are there to do what those people require, not what they - the worker- think needs to be done.

One of the things that we're finding with some of the training that workers undergo, they come out with knowledge about how to do certain tasks in one particular way, and they're inclined to push this onto people with disabilities. Certainly we would like to see them learning how to listen and to be guided by the person they're working with, and also for people with disabilities to gain the skills in directing people in a way that is respectful and works for both of them.

MR WALSH: Thank you.

MR KALISCH: I was interested in the aspect around the distinction you drew between the assessment process and the funding and then the service provision. I can understand how you might have a difference between assessment and service provision so you don't get direct conflicts there, but I suppose the one aspect I wanted to talk about or ask you a question about was really the funding question, as distinct from the funder, why you'd actually have that distinction. I suppose the question I'd ask is would you actually run into issues of scheme viability if you had decisions about funding levels made distinct from the actual funder itself?

MS McNAMARA (AFCL): The funder would still make the final decision, I guess. That's the reality. If the initial assessment is done from the perspective of keeping costs down, that's where I think the problems come in. There needs to be that scope to explore what people need without that constant pressure of, "My boss is over my shoulder." That's why I was saying they need to understand the funding issues and the eligibility requirements and the funding constraints, if you like, while not being actually totally driven by that.

MR KALISCH: So would you suggest there be a more strict or structured way of doing assessments or should it be more flexible?

MS McNAMARA (AFCL): I think there's probably ways of having a clear framework around it without necessarily having a tick box check list and that it always has to be done exactly that way. Victoria is grappling with this stuff at the moment and I think perhaps the system here is a bit top heavy, but there's probably something to be learnt from looking at the planning process and how it's being done here in terms of giving people the chance to talk about how they want their life to be and what sorts of supports they might be able to get that don't cost anything, that are available in the community or through their informal support networks and then what they might need in addition to that, that would come through a package.

MR KALISCH: Have you seen any models or benefits of different types of people, different professional qualifications or experiences that enable people to make better assessments?

MS McNAMARA (AFCL): I wouldn't put a professional label on it but people who have extensive knowledge of disability, either directly themselves or through working with people, it's not a medical thing. It might be allied health workers. Occupational therapists often do it well. It needs that more overall approach and certainly, while I think there are many good doctors it's probably not doctors.

MR KALISCH: Have you seen benefits of teams of people working together around assessments or can individuals make those good judgments?

MS McNAMARA (AFCL): I think it probably depends on the complexity and needs of the person. I've worked in the acquired brain injury field and for somebody with very high level needs it may need a team approach. I think for a lot of people it could be one person. I was talking to someone the other day and they were saying, "Look, maybe this workforce doesn't yet exist and this is another workforce that we need." There's a series of skills that people need that we could develop in a particular workforce.

MR KALISCH: Just one more question about assessment. Obviously not all initial assessments will be accurate. There will be some mistakes made at different stages because people are just human. Have you seen or experienced good or bad appeal processes and how poor decision-making can be corrected quickly?

MS McNAMARA (AFCL): I can't pinpoint any particular ones at the moment. It needs to be fairly readily accessible and that's often not the case, and certainly as easy a process as possible because sometimes people get lost in the maze and it's just too hard so they give up. I guess whatever system it needs to be readily available and reasonably speedy so that people aren't waiting for years and literally it can do that.

MR KALISCH: Okay, thank you.

MS SCOTT: Sue, do you have choice in your service provider now?

MS WHITING (AFCL): Up to a point.

MS SCOTT: Do you have an individualised care package now?

MS McNAMARA (AFCL): Your agency administers your care package? Assists you? "I don't work to a care plan," Sue says. "How many people in this room have a care plan?"

MR KALISCH: Yes.

MS McNAMARA (AFCL): I think one of the things that people say is there's that frustration about, you know, "I'm supposed to plan my life." Not everybody else has to plan their life down to the nth degree.

MS WHITING (AFCL): Yes.

MS McNAMARA (AFCL): It shouldn't have to be quite that rigid and controlled.

MS SCOTT: Yes, okay. What difference could a national insurance scheme make to your life, Sue, do you think? There's more support you need? More opportunity to put back into the community?

MS WHITING (AFCL): Yes.

MS McNAMARA (AFCL): Instead of being put on a waiting list.

MR KALISCH: So get things as you need it?

MS WHITING (AFCL): Yes.

MS SCOTT: How long did you have to wait for that chair?

MS WHITING (AFCL): 18 months.

MS SCOTT: 18 months. Okay, thank you.

MR KALISCH: I suppose one question just about the advocacy dimension, if there was a better system that provided support for people when they need it would there need to be as much call for advocacy?

MS McNAMARA (AFCL): Certainly not as much. I think there still would be call for it in terms of people accessing the system, so before they even get into the system, still there's people who fall through the cracks in any system but certainly hugely less. Our advocates who work with individuals say that a lot of their work is just about the fact that people don't have these things that they need, so you're trying to shore up a broken system.

MR KALISCH: People struggling to get the few resources that are out there.

MS McNAMARA (AFCL): Sue gets 34 hours.

MR KALISCH: Yes.

MS McNAMARA (AFCL): It was okay years ago.

MS SCOTT: You need more now.

MS WHITING (AFCL): I'm not going into a nursing home.

MS McNAMARA (AFCL): Yes, Sue is not going into a nursing home. We know that the youth issue is going to be addressed after lunch, and we work with people of all ages, but certainly for a lot of people who are getting into their 50s and 60s there's that sense of, "If I don't get more support I'm going to end up in a nursing home and that's not what I want to do," and to the extent that I know people who are thinking, "Well, if that's what it is, I'd rather die." People are doing things to stretch their hours. We've had stories about people who in order to stretch the hours after their early evening attendant has been there, they get on the toilet and wait there until their later evening attendant comes and then if that person doesn't turn up, they're sitting on the toilet all night. Sue's got a friend who buys all her meals precooked because there's no time to have somebody assist with cooking.

MR KALISCH: Yes.

MS SCOTT: John, any further questions?

MR WALSH: No thanks, Patricia.

MS SCOTT: Thank you very much.

MS SCOTT: Well, I think we're ready to resume now. So I'm welcoming to the table Wesa Chau and Licia Kokocinski. Well, I might get you to identify yourself for the tape and also to explain your organisation and your role in the organisation. Thank you.

MS KOKOCINSKI (ADEC): Okay, my name is Licia Kokocinski and I'm the executive director of ADEC. ADEC is Advocacy Disability Ethnicity and Community and I have also with me Wesa Chau who is one of my senior managers. She is manager of Direct Services. I want to thank the commission for the opportunity of appearing today.

ADEC has really a couple of functions. It's about assisting people to get on with their lives, and we only work with people with disabilities from different ethnic backgrounds. We would probably work with 45 different ethnic groups or language groups a year, three to five hundred people per annum. At ADEC we do three things - doesn't matter when you get away from all of the NOVA vision mission, all that sort of stuff - we work to include people in society, we build bridges for people and we empower them to make sure that they can make their own decisions on their own and supported, if necessary. We have been on the scene for 25 years and changed over the years, most certainly, but still in its main role of advocacy.

The formal submission, I'd like to say, will be forwarded to the commission once it's complete. Due to its mandate our submission and comments are therefore confined really to a Victorian perspective. It's important that ADEC sets the scene for the commission. Back in 2000 when the Victorian government was developing its own 10 year disability state plan, researchers found that only about 4 to 5 per cent of disability service users came from diverse cultural backgrounds, so it's a very small percentage. Given that disability occurs at the same rate across all cultures, even though disabilities may be different, and that 25 per cent of the Victorian population come directly from a non-English speaking background, the figure that I have just tabled tells you that there is a very large disproportion of the population missing out. This has consequences at every level of society as well as for the families.

Most of the people who come to ADEC are benefit holders relying on disability service pensions and other benefits of income. I would say 99 per cent of them are benefit holders. That in itself is a problem for our constituency because we spend considerable effort in educating individuals about their rights and entitlements in this regard. I would like to bring to the commission's attention that we will be working with the National Ethnic Disability Alliance, NEDA, to work up their own submission and NEDA is a peak body that speaks on behalf of other organisations working in this same space. I'm not too sure whether you've heard from them already but I'm sure that they will be making a submission.

We congratulate the commission on the breadth of its inquiry and especially the sophistication of the discussion paper which I think we would all agree is very comprehensive and outlines very clearly what some of the issues are. We believe it canvasses the issues very well and especially the implications of any long-term scheme on a federation such as Australia with fairly rigid constitutional arrangements and indeed, the problems of implementing such a scheme.

ADEC asks where and how a national support scheme links with a national disability strategy. Due to the COAG arrangements initiated by the new government upon its election in 2007 the responsibility for disability services was virtually fully bestowed to the states. The federal government's responsibility changed to setting directions and broad policy design accountability and setting benchmarks, although we do acknowledge that the federal government retained some involvement in some mental health and autism spectrum disorder services.

The dispersion of responsibilities may make the design and implementation of a national scheme very difficult, and you only have to look at how the debates and the argy-bargy regarding a national water scheme or hospital health funding scheme was progressed or not progressed - and probably throw into that the education discussions - depending about your point of view whether you think it has progressed or not. The torturous debates about state jurisdictions and responsibilities can and very often does lead to some pretty poor policy outcomes, though we know that there have been some terrific gains like the Medicare situation. Inconsistencies between states in the funding and provision of disability support services is manifest in Australia. Western Australia and Victoria probably have more invested in providing services to people with disabilities than any other states.

In the past ADEC has undertaken a number of focus groups involving several ethnic groups on various issues relating to disability support and services. No amount of tinkering, redesigning or shape-shifting of the disability support system as it is can run away from the fact that there are simply not enough services for people requiring support. The most common complaint that we hear from the people who come to ADEC are simply that there are just not enough services. There is not enough funding for direct services nor for respite. The services that are there are often poor quality. There concerns about high staff turnover. There is poor case management and, more importantly, poor access to current services.

When people eventually are able to access them they are confronted by long waiting lists, frustration levels are high, people say they are not being given the same information as people who speak English well and generally they are treated less well than their English-speaking counterparts. People identified the need to provide education in their own communities and to the general community about disability and to improve general public awareness and acceptance of people who don't fit a norm. People at ADEC would say, to be quite honest, they don't care who delivers services or how they are controlled or governed. They just want decent, timely and accessible services. In fact, whenever we do a focus group the state, Commonwealth jurisdictions, local government involvement is completely - doesn't matter and people don't understand the differences, but unfortunately we as service providers have to take note of that because they control what we do. I would say that there's a very high level of cynicism in the community about improvements. I have to say at this stage that we at ADEC do support the principles of a national disability insurance scheme and taking on a national approach.

The initial comments coming from the paper are these. There is some discussion about providing packages for people. What we would state right from the beginning is that language services, interpreting services, should not be part of any support package because this immediately wipes out probably half of any money available. I know that in some jurisdictions this is happening and it means that people are actually being denied 50 per cent of their rights to support. ADEC agrees that any scheme should cover disability acquired at birth, through accident or health conditions but not due to ageing. However, as people with a disability are living longer, the longevity of people with disability living into old age has to be taken into consideration.

The paper indicates that a scheme would not be available for people with a disability who may need few or no supports and be mainly targeting people who need significant supports due to their profound or severe disability. This is in fact sound public policy. However, due to the poor perception and acceptance of people with disability in society this makes inclusion in normal society problematic. There is ample evidence to show that people with even low disabilities actually hide their disabilities. You point out in your paper that there would need to be some assessment where people are in or out, but unfortunately people fight like tooth and nail and often are - and we know in certain areas - are given particularly different diagnoses than the conditions they really have, just to access services. I'd like to talk a little bit more about eligibility. A couple of points about eligibility to any system. The impact of a central insurance scheme - on people who cannot become Australian citizens and may still have to pay compulsory premiums but who have a child with a disability and therefore will not be able to access funded services - is an issue.

I have to say that one of my staff members is in this situation. She is a New Zealand citizen, can never be Australian citizen, because she has a child with a disability; yet if we bring in a national insurance scheme - again, which we support the principle of - this person will never be able to access what is available in that scheme, as we hear it. I think that this is all bound up in the whole issue of the disability and immigration debate, to which we have also contributed. I think you need to bear in mind that not everybody will be accessing any central pool.

Secondly, assessments for eligibility differ within states, and even within silos within states. For example, assessments for supports used by, say, the Department of Education and Department of Human Services use different measurements for support. So we find that even where there is intellectual disability there is a lot of difference between what Disability Services can provide and what the Education Department can provide in relation to supporting a child at school. I'm not too sure how you reconcile that, but I have to say it's going to be greater heads than mine that should be able to do that.

Assessments can and do work against people with disability from ethnic backgrounds, because of incorrect diagnoses and/or assessments. Who makes the decisions? ADEC supports the principles of individualised funding or consumer-directed care but believes that when this is fully rolled out people with disabilities from different ethnic backgrounds will miss out in very large numbers. This is because such a scheme has as its basic assumption a level of education, understanding and ability to ask the correct questions, and that, in ADEC's experience, is missing from the people who come to ADEC.

Any formal service must have the availability of advocacy on their side, mainly to redress the points that I have just made above. For people who come to ADEC the key issue is service coordination and linkages with mainstream. Getting back to the advocacy, you mention in the discussion paper the capacity to access mentoring. I think I would add a third string to that, and that is advocacy, because the systems are very complicated, even for people who are well-educated. In fact, one of my board members, who is now a carer, in a situation she would never have thought to find herself - this lady travels the world delivering high-level papers for people who are hearing-impaired - was just reduced to tears when she had to fill out carers allowances and all that sort of thing.

This is for a person with a very, very high level of tertiary education. So if she struggles, what about the punters who have never gone beyond primary school. I think we need to understand that across Australia. So for the people who come to ADEC the key issue of service coordination and linkages with mainstream issues is extremely important. I think Wesa will talk a little bit about that. The paper states that one of the challenges in coordination may be compounded by the fact that many services are government-funded and delivered by government. This will continue to be a problem.

What I'm going to say is rather contentious, but I keep pushing this barrow. It's going to continue to be a problem while government is in the business of providing services. In Victoria, services provided directly by government are much more expensive than services provided by the not-for-profit sector. So what benchmarks will a national scheme use for sourcing or funding services? I think that that's an issue that has to be addressed, because I know that the not-for-profit sector can deliver good services at a much cheaper rate than the government sector. I'll now pass over to Wesa.

MS SCOTT: Just before you do, would you be happy to have some questions now?

MS KOKOCINSKI (ADEC): Sure.

MS SCOTT: Do you have any material you could provide us on this cost differential between public and private provision?

MS KOKOCINSKI (ADEC): I can try and get them, because I'm involved with a lot of not-for-profit providers, and certainly we can talk about it. I can give you one example, with respite. I think Wesa can probably give you much more on the hourly rate - and we run a small respite service - but the hourly rate that we pay for a respite provider would be anything from $5 to $8 an hour less than what the government pays, and I know that's great for the workers who work in it. But it means therefore that, while we get a unit cost per hour from the government to run a respite program, in the government sector they'd pay that money for a wage.

Out of that hourly rate that we get from the government we have to pay the wages of the respite worker plus the oncosts plus the coordination, the matching, the training, all that kind of stuff that is really key to running a good service. Governments don't face that problem; but we do, in the not-for-profit sector. I'm sure that there are other circumstances where there might be some data available. But I think that it is something that's needs to be factored in when you're setting benchmarks.

MS SCOTT: I just want to test that a little bit more. Even snippets of information can be fruitful for us, because we can explore them further and so on. One of the things we actually have to do is cost the proposals that we end up bringing forward. That's quite a task, costing services where you're not too sure what the unmet need is and costing services that don't necessarily exist now. This is quite a challenge. I just want to go back to your idea, this information, that respite services that you provide are costing you to $5 to $8 less. You said that you have to cover training and you have to cover oncost administration. But why wouldn't the state service also have to cover training and so on?

MS KOKOCINSKI (ADEC): They do, but there's some political and industrial relations realities here, that public service unions have in the past been very powerful, they have been able to extract good agreements; and good on them. The workforce in the not-for-profit sector is largely ununionised. As we all know, it's effeminised, as it would be in state-funded system. The government is essentially the only purchaser of services, so using a free market model isn't a good one, because there is only one purchaser, and that is the government. It can determine and dictate the price that it will shell out per - whatever the unit costing. They can determine that.

In fact we found ourselves in quite a deal of bother when, because of the COAG arrangements, the respite programs shifted from the Commonwealth to the state government. Under the Commonwealth jurisdiction there was some flexibility for us to negotiate a price, and then we find that when it was shifted to the state we lost that capacity, and in fact we were told, "This is it, there ain't no more." That, unfortunately, means that sustainability is an ongoing problem.

MR KALISCH: It was just that question of sustainability of that arrangement that I was going to ask you about. Do you cross-subsidise your service provision from other funding you receive, or are you able to use the funding you receive for services to cover all of the costs?

MS KOKOCINSKI (ADEC): No, at the moment it is not making any surplus and it's not breaking even. We have had the respite program for three years now. Admittedly, we started from nothing. We received some funding from the Commonwealth under its Ageing Carers Program, when it was still involved in it, to set it up. I know that there is a lead time between commencement and when it's fully funded, but we really need at least another 10 to 15 packages to make it sustainable - that is, break even. At the moment we run 19 respite packages, we provide respite to 19 people; we need a minimum of 10 - probably 15 more, to actually make it break even. So we are subsidising it. We have been discussing the budget, only yesterday, and we do have quite severe restrictions on our funding, because the moneys we get just don't keep pace. Yes, it is being cross-subsidised.

MS SCOTT: Is your respire in-home respite?

MS KOKOCINSKI (ADEC): It's in-home respite, it's also out of home. It's in-home respite, but we also provide recreational opportunities and other types. There's two components to it: one is the funded in-home respite for people who are a bit more dependent and need some ongoing support; and then there is also another one, for which we use volunteers. The volunteers can take people out; we can organise outings or a friendly visiting type of service. So it has two prongs to it.

MS SCOTT: Thank you. Wesa?

MS CHAU (ADEC): Just to add to Licia's point that it is important to note that any scheme must be family-oriented, because, in our experience, we agree with the individualised approach that we focus on the person with the disability. However, the reality is for people from non-English-speaking backgrounds that they generally operate as a single unit. If any scheme focused only on the person with the disability it's likely that the person with the disability will not be able to access that service, because there will be a family barrier there. So the needs of the family also need to be taken into consideration.

The schemes will need to also be flexible enough to meet the needs of people with disabilities, and it should be demand-driven rather than supply-driven. At the moment it's very much a supply-driven model. Also the stability of the workforce is also vital, in order to deliver a quality service and hence a quality system. There also needs to be measures to ensure that there is stability in the whole workforce - so a change of government should not alter whether or not agencies get funding - and support to people with disabilities. To ensure people of diverse backgrounds are taken into consideration at the start, I think there needs to be a person with expertise in cultural competence engaged in the design phase, as a core team member rather than engaged during the review stage or as a consultant later on down the track.

MS KOKOCINSKI (ADEC):   It's really important that any system that is designed takes into account that we do have a very, very diverse society. I know that appears to be stating the obvious, but you would be surprised how often systems programs are designed and then they wonder why years down the track people from different ethnic communities aren't using the service, or they might use it once and you never see them again. It's not rocket science, but I'm just always surprised how new systems and services, programs, seem to have complexities not built in. Life is complicated, society is complicated.

MR WALSH: Licia, I'm interested in this issue, and I was going to ask before about the lower utilisation of services by people from ethnic backgrounds. It has been pointed out to me previously that often this is because of the family structures which take responsibility for looking after people with disabilities. I'd like just some comment on that issue.

MS KOKOCINSKI (ADEC):   There's a number of things that one can say about that. It is not correct to assume that families will look after their person with a disability. As is always the case, it's usually left up to one person; the mother or a sister, but usually the mother. What we're talking about is stigma, we're talking about shame, we're talking about lack of knowledge about what is available in the rest of society to support the family. So there's a whole multitude of issues and a whole multitude of things thrown into the mix. It is incorrect to stereotype and say that families want to look after their own. I think every family wants to do the right thing by their person with a disability, regardless of what their ethnic background, and I'm also including in that white Anglo-Saxons as well.

I think everybody wants to do the best they can. However, if you don't speak English, if your cultural background has loaded in it a whole range of myths and beliefs, then that is going to complicate access to services. We are dealing with stigma, myths, beliefs all the time, but it can only be tackled at a grass roots level, working in communities in their languages and where those communities are at. Things like health promotion and a whole lot of other things really don't work, and just developing brochures about the particular type of service doesn't work either.

One of the big issues that we deal with with many service providers is that, "Look, if you wait for the people that we work with to come to you, you're going to be waiting a long, long time, because they're not going to come. You actually have to go to them. You have to go and show your wares. You have to make your service appropriate, empathetic, understand where they're coming from," and go to them essentially, not wait for them to come to you. I think that's true in just about any good service, isn't it?

MR KALISCH: Is that going to be possible, to do it on a service-by-service basis, or is that something where a case manager or sort of a central coordinator can play that brokering role.

MS KOKOCINSKI (ADEC): At agency level, like, if you're talking, say, about a community health centre or a respite provider, at that grass roots level, that down-on-the-ground level, I think it is really important that those organisations need to do the bridge-building and go out to the communities themselves. They need to be looking at the way their services at that grass roots level are structured, the calibre of their staff, the whole concept of cultural competence is absolutely imperative and implementing cultural competency, not just knowing about it but really going out and talking to communities and going to their clubs and going to their meeting place, you often find people meet and congregate, going to those places and talking about it, and using a lot of informal networks that do exist.

ADEC and NEDA and all of the organisations, we can do our bit, but ultimately it is the responsibility of service providers, because the people that we are talking about are part of society, they are part of the mainstream, they are not just tacked on on the sides. So there are responsibilities. Everybody has responsibilities. Individuals have responsibilities to learn for themselves, but organisations also have those responsibilities as well.

MS SCOTT: We were speaking yesterday to a provider, an insurance model provider, and they were saying that somebody had an injury the week before and they were going in with their team of support to start talking to the person the following week. You can imagine that with a national scheme along the model that some people have proposed in the disability insurance group work that in some cases you might be initially having contact with people at a hospital or a paediatrics office, for early identification. But with your group of clients where they might have been 20 or 30 years outside a system - - -

MS KOKOCINSKI (ADEC): And they are.

MS SCOTT: All right, 40 years outside the system. If a new national scheme was introduced - I mean, you're not everywhere - how do we make that contact, interface? I can understand where you are, of course you think, "Well, we're the way to achieve it here," but what about where you don't exist? Could Centrelink be a point of contact, given that you started off saying that 99 per cent of the client base are benefit-holders.

MS CHAU (ADEC): I think any agency can possibly do that work if they're culturally-competent. If they go out and actually talk to people, if they are community orientated, if they can communicate with people properly I think it's possible, but at the moment that's not happening. That's why agencies like ours, we've got advocates to actually assist people and to help them get access and that's probably one of our major problems for our clients.

MS SCOTT: Okay.

MS KOKOCINSKI (ADEC): It really is not rocket science. I mean, we're really talking about agencies and organisations understanding who their target group, who their clients are, and not segmenting it up to who is going to be easiest to deal with which is what happens now. In relation to Centrelink that is a good suggestion because in our focus group Centrelink comes up all the time and there is a very high reliance on the information Centrelink puts out. Now we know that Centrelink has its own issues, I mean, you have staff who are stretched, who are pressured, who get people that come to them that are probably aggro, so there are some issues. We can't just keep dumping on Centrelink all the time, but whenever we talk to any of our people in these focus group settings - like, we're going to be doing some more focus groups in the next month on national quality framework - I will bet my house on the fact that they will bring up Centrelink because that's who their interface is with all the time. So it may be a good start and that may be one appropriate vehicle because everybody knows Centrelink. They know about it, even a little bit.

MS SCOTT: Yes. I'm just conscious of time, John, any further questions?

MR WALSH: No, Patricia, but it is an interesting discussion. I think it sort of extends the idea of early intervention to another dimension which is cultural intervention as well, doesn't it?

MS SCOTT: Yes, I think that's right. I wonder whether we could implore upon you, when you're putting your submission in you might think about the challenges we face in terms of - you know, it could be a large national roll-out of a scheme and how would you communicate effectively and culturally competently with a mass audience. We're not natural experts and you might steer us towards people that you feel are experts.

MS KOKOCINSKI (ADEC): Yes, we'll certainly come back to you.

MS SCOTT: Thank you very much, and thank you for the opportunity.

MS SCOTT: Our next person coming forward is Raelene West. Welcome, Raelene. Would you like to make an opening statement? Are you representing any group?

MS WEST: I'm representing myself actually. I study at Melbourne University, so I'm a university student doing some research into disability support services and also compensation pathways.

MS SCOTT: Okay.

MS WEST: But I'm also here I guess as an individual with my own experience of an individualised support package and I'm funded by the Transport Accident Commission, so what I'm presenting today is a combination of my own research at the university but also some of my own experiences of the system.

MS SCOTT: Okay. Thank you.

MS WEST: The provision of resources to support people with a disability in Australia has traditionally been complex. Some European settlement in 1788, a mix of both formal and informal models of funding have supported disability, predominantly within institutional settings. Based on emerging international models of deinstitutionalisation, the Independent Living Movement and the social model in the early 1970s, policy responses shifted from that of segregation and deinstitutionalisation towards one of institutionalisation and social inclusion, supported by a model of community based care.

The Disability Services Act in 1986 was implemented as a dominant piece of legislation that would oversee the establishment of this model of community based care for people with disabilities. The Commonwealth, State and Territory Disability Agreements were established to support a Disability Services Act in undertaking this role. The CSTDA's aim to creating administrative efficiency and clarifying funding roles and responsibilities between the state and territories and the federal levels of government, given the large expansion in service delivery that was required in establishing a model of community based care.

As with much of the Australian health system the split between the Commonwealth and the state territory funding parameters in jurisdictions led to duplicity in operationalisation of administrative practices and a multiplicity in service program delivery that has created fractures, lack of uniformity and lack of equity in the delivery of disability services at a national level. Determining accurate levels of usage of disability services and monitoring and contrasting different levels of service delivery across Australia have until recently been significantly hampered by the multilevel, multi-state delivery of services.

In addition, the failure to include HACC services, CRS programs and insurance based funding of disability services, such as those received through WorkCover and transport accident schemes, and disability funded privately as a result of public liability claims within the structure of the CSTDAs have distorted the view of how disability service delivery is truly funded or not funded across Australia. This fails to provide an adequate picture as to the many inadequacies in funding across Australia. In terms of provision of health and community service programs related to disability service delivery, despite a population of only 20 million people in Australia, the AIWH has estimated that state, territory and Commonwealth governments are responsible for more than 60 programs and services within and outside the CSTDAs.

For any one state, disability services are funded by between four and eight different funding providers inclusive of services under the CSTDAs, but also inclusive of transport accident schemes, WorkCover schemes and services received through federal funding schemes. These have evolved over many years and have evolved on an ad hoc basis in response to specific needs and demands. This framework is also characterised by its siloed in jurisdictional funding approaches, the disability service delivery.

As with many proponents of a national health system, a move towards a nationalised funding of disability services would ensure the removal of many of the current framework structural problems. A nationalised disability services framework would provide a more equitable means of assessing, monitoring and delivering the wide scope of disability services required. Most readily, a shift to a model of service provision based on individualised support packages within a new national framework would improve equity and support provision and increased choice of flexibility for people with impairment and in turn meet obligations of human rights as defined by the UN Convention on the Rights of Persons with Disabilities.

Further, I feel maintaining the role of common law claims within a new NDIS system in a national support framework would be crucial. I feel compensation plays an integral role in providing redress and rebalance for both on an individual and a social level following the acquirement of an impairment, or a significant level of fault and negligence has been attributed to the cause of the impairment. I feel this would most effectively be achieved if a system similar to that of the Victorian TAC system was expanded at a national level on an NDIS platform. The TAC system retains a common law component for the serious injury where fault can be proven to be claimed through the courts, or general support services, accommodation, medical and general entitlements remain within the standard TAC division. I feel without an opportunity to claim for compensation through a common law plan, where income and all livelihood was lost as a result of the acquirement of the impairment and where there was fault, would be introducing a different form of injustice to the arena and that these areas would be difficult to address solely under a support services platform.

I feel a structure for a common law plan could easily be placed within an NDIS platform or a national support framework, as with the TAC hybrid system where common law claims would be capped so as not to draw too great an amount of funding from the overall general funding pool. In general, I believe compensation provides scope for an individual that has acquired an injury to make significant life changes required as a result of acquiring a permanent impairment, such as needing to repurchase more accessible homes, private vehicles and continuing to meet established financial commitments for work roles or providing income for existing dependents.

I feel this is a good opportunity that we have this moment to make a significant restructuring of Australia's support framework for people with impairments that would work towards supporting individuals with an impairment, and families of individuals with impairments, to achieve their desired goals and explore their full capabilities. That's just my overall opening statement.

MS SCOTT: Thank you. I know David and I were looking at the material you've already provided which is quite extensive. I wonder if, Raelene, we could focus on your experience and your insights into TAC, and the fact that you want to retain an element of fault in the system. Have you looked at the NZ model at all?

MS WEST: Yes, briefly I've had a look at it. I understand that it's a more universal system where everybody is on the same system and everybody receives a uniform level of support services and entitlement. I believe they have removed the scope for common law.

MS SCOTT: Yes, I think they have, haven't they, John?

MR WALSH: Yes, I think either common law never was in the scheme or was removed 20 or 30 years ago.

MS WEST: I think, from what I understand, there are some avenues to claim for common law but these are reduced. So significantly lower levels of compensation are received and they're more like scheduled payments and they're automated payments, rather than going through a court based system.

MS SCOTT: Could you elaborate a little bit more - you've said it would be a different form of injustice to do away with a fault based system.

MS WEST: Yes.

MS SCOTT: Could you elaborate a bit more on that. I mean, it's a costly system to have a fault based system, it could take a long time and so on. You've probably heard a lot of reasons over time about why people see fault with a fault based system. Why do you see merit with a fault based system?

MS WEST: Particularly, I guess, where there has been fault in how the impairment has been acquired. I think it gives an opportunity for someone to have their story heard and to voice their experiences and what has happened. It gives the courts an ability to explore what has actually happened, and all of the arguments that I have listed in the submission - I'll just refer to my notes here - in terms of rebalancing and re-levelling circumstances; in identifying responsibility in terms of how the accident was acquired. I think it just gives an individual some accountability and rebalance on a personal level as to what has happened. It allows the courts also to mark their disapproval at the negligence and the misconduct that has happened. It also provides avenues for appeals in case an individual is not happy with the outcome which is more detailed in the submission.

It gives you more of a scope to negotiate and go through the payment and to argue out some of the levels of payment that might be acquired, particularly around medical statements being made by the practitioners, and assessments made by medical practitioners. It gives you a chance to have all of that negotiated and all of that to be questioned and thoroughly gone through, rather than a system being automated and you not having any opportunity to input or contribute to the assessment being made.

MS SCOTT: You also made the valid point about loss of income.

MS WEST: Yes.

MS SCOTT: I probably want to go down this route a bit further but I don't want to monopolise the question time. John, do you want to - - -

MR WALSH: Yes, I have a question, Patricia. You talk about injustice if common law is removed. How do you feel about the equity between someone who can prove a fault of a third party and so is entitled to common law, and someone who can't prove the fault of a third party but has an identical injury? How can you reconcile the equity between those two avenues of compensation pathways?

MS WEST: I guess initially any catastrophic injury that has occurred in any weight of its forms is a huge impact on a person's life and has to be dealt with. But I think the particular issue of there being fault and how it occurred does need to be addressed or does need to be explored. I guess if somebody is wheeling down the street and they're on a skateboard and they trip up on something and they have a major injury or a spinal cord injury and break their neck, that's a serious impact on their life and it's a serious thing. I guess you could call that an act of God and it just happened and there's no particular fault to it. It is devastating but where there is particular negligence on behalf of either a workplace in not providing a safe area of work, or whether there's particular fault in someone driving in terms of you're just driving down the road, meeting all your social obligations in following the road rules and someone is a drunk-driver and totally wipes your car out or disobeys a traffic signal or something to the point that you're injured, specifically because of the wrong act or the negligent act of another one, to then not have any redress or recourse about that I think is unjust.

Also in terms of criminal acts, like you're the victim of a shooting or something and you become seriously injured or have an acquired brain injury or something, that's an act of another person who should have known their social rules, social boundaries or value systems of society - has crossed a boundary basically and this action has occurred and resulted in the harm and serious injury of another person. I think it sits at a different level than somebody just on a skateboard tripping up down the street, even though both of them are very serious and the impacts can be quite devastating for the individuals.

MR WALSH: Yes. I suppose I'm interested in your comments on where the areas are a bit grey. Say, for example, a person with the skateboard going down the street tripped up on a crack in the sidewalk which could arguably be attributable to council not maintaining the footpath properly, how much dispute and litigation do you think is reasonable for that person to try to prove the fault of someone else which may take many years and divert them from their rehabilitation and so on?

MS WEST: Yes, I believe they should have a similar pathway regardless of whether it's the liability of a council not doing the footpaths, or a car accident or a criminal act or workplace negligence in terms of the set-up of a workplace. All people that are in the disability service system should have a similar avenue to access the courts. I think they should all go through the courts. It shouldn't be just some go through the courts and some don't go through the courts. They can all go through a similar pathway of having the courts assess the circumstances of the injury acquired.

I understand that the courts have worked very hard recently in reducing the time it takes for a case to go through. So I think they were extending out to four, five or six years at some stage for an outcome to be achieved, but I understand they have really worked hard at reducing waiting lists and then reducing the time that it's taking for these things to go through the courts. That's just another note on the side. I would see a pathway for anybody that has acquired an impairment to go through the courts. It wouldn't be just specific to either a car accident or WorkCover. I believe they should all have an avenue. There's certainly scope under the Transport Accident Commission for the claims to be capped. We're not talking about - there wouldn't have to be multi-million dollar payouts or compensation payouts. Like there's certainly - an avenue such as the TAC whether they're capped at something, a million dollars or something. But at least where - you know, any injury that occurred or any impairment that was acquired there would be scope and a pathway for them to go through the courts and receive at least a limited compensation payout or a capped compensation payout.

MR WALSH: Would you extend that right to go to the courts to people who might have acquired their disability in other ways, for example, in a hospital or in a medical diagnosis?

MS WEST: That's a very big question. I guess having said the other things you couldn't have the other five options and then not have that option. But I guess that would be - I think probably more debate and more discussion needs to be had on that. I guess my personal view would be that yes, they would.

MR WALSH: Thanks, Patricia.

MR KALISCH: Raelene, just on that issue of compensation, I mean could you envisage other structures being put in place such as administrative arrangements and schedules for payment rather than having to go through probably what can be quite a confrontational legal arrangement?

MS WEST: It wouldn't be my personal good view - I mean it wouldn't be my personal view that that would be as good a way of doing it because I think the whole reason that you have the court structure is so that you have an opportunity to negotiate and argue and state your claim and to sort of explore the intricacies and the details of what happened in terms of the acquirement, whereas an automated payout system, although quicker, I just think it detracts from that whole system of actually what the compensation is in terms of providing redress and rebalance and the individual having the opportunity to sort of go through events and for people to be made accountable for their actions. I think an automated payment removes that responsibility and that accountability to some extent. An individual that has caused another person to have a serious impairment - if an insurance company simply just pays an automated payout to them they don't have any weight or burden or conscience put on them in terms of the actions that have occurred, you know what I mean? It's just a separate insurance agency just giving somebody some money basically. I think it just detracts from the whole system or it's very distant from that accountability and responsibility.

MR KALISCH: One aspect that has certainly been raised with us is that obviously the legal system does not come from free, that there are obviously quite significant costs and quite significant costs that can go mainly to lawyers rather than necessarily to the recipients of the injury. I suppose one of the aspects that has certainly been raised to us about moving towards more of a no-fault system is that you do actually remove some of those deadweight costs of lawyers' fees. John also mentioned the potential issue of disincentives to undertake rehabilitation because you've got to prove not only negligence but also the degree of suffering and disability that you've received, which over a number of years can discourage people from rehabilitation. Are there ways of, I suppose, ensuring that a court-based system has lower costs or doesn't discourage rehabilitation at an early stage?

MS WEST: Yes. But I guess one point I'd like to make is I think you're in danger of maybe losing the expertise that the courts offer and the expertise of a judicial judgment and the expertise that the court system can offer by just going to an automated system. So I think you need to sort of note that, I guess, in terms of what the actual role of the courts are and traditionally what their role has been in determining these cases. There is a lot of expertise and knowledge and precedent there as to making assessments and decisions in these areas. So I guess my first and initial comment is to make a note of that. Your second one in terms of the rehabilitation - - -

MR KALISCH: Disincentives for rehabilitation, yes.

MS WEST: Yes, I do see them as sort of very separate things because I do see the compensation role as very separate from your support service provision. I think that is - once you initially have an injury, just I guess from my personal experience, your immediate concern is just getting your support provision up and getting your attendant care and getting your houses modified and getting vehicles modified. Yes, that's a compensation thing but I think there is certainly scope for that to happen later. If it's, I guess, an income-based thing similar to what TAC do, they just run you on basically a - you know, you get a payment every two weeks until your court case comes up and then you run the court case. Your income is very separate from what your rehabilitation, in terms of support and getting back to your home is. So I guess I see them as two separate things.

I guess if you can promote that, yes, this court case and the assessment of blame and fault and everything will be happening to somebody, you know, but it will happen at a later date sort of after their rehab has occurred and maybe focus on just getting them home first and getting them set up with their attendant care and adequate amount of hours. I think that you can certainly maintain that balance and it shouldn't be too much of a disincentive providing the court cases are brought forward and not taking too long to resolve. So if they can be resolved in sort of maybe the first - after the first year or two or three rather than it being four or five. I don't think it would act as too big a disincentive.

MR KALISCH: Just one more question for me on this aspect: do you have any sense of what the cost of the lawyers' fees and the court-based costs are compared to then the final payouts?

MS WEST: I understand they're high but I wouldn't want to go on the record as to quoting them. I think that's maybe for the legal practitioners.

MR KALISCH: I was just wondering whether you had any sense of whether it was sort of 10 per cent, 50 per cent, 70 per cent? I mean if you don't then - - -

MS WEST: Well, it could vary. It would vary on the size of the court case and the length of the court case, I imagine. I think for each individual case it would be very different. So I'm not going to sort of put a - - -

MR KALISCH: Okay, thank you.

MS SCOTT: Raelene, I appreciate you're here in part as a PhD candidate but I wondered whether you'd mind talking a little bit about your experience as a TAC client. Some of the other people who have given evidence here today have talked about 18 month waiting times for chairs and 12 month waiting time for appointments and so on and having to get the basic equipment. Is that very similar to your experience with the TAC? Have you had to wait long time for each piece of equipment that you've been assessed as desirably having?

MS WEST: No, it hasn't been my personal experience. I see the TAC system as a very good system. They've been very responsive to need. They certainly have a level of accountability. You can't just sort of put up your hand and ask for anything, they have to go in there and they do OT assessments and things like that. But there certainly is a waiting list and they're generally - they have enough funding there to provide things that would be reasonable. Most equipment has been provided sort of just fairly quickly after an OT assessment, things like that. My experience of TAC is, you know, they're certainly definitely accountable in terms of the funding but they're certainly very reasonable in what they will provide. They're certainly - if you can sort of show that you have need for attendant care hours or need for services and service provision or equipment there hasn't been any delay. They have an adequate funding pool behind them, enough that they can supply these things much quicker. Just in terms of that I've recently shifted too onto the individualised support package.

MS SCOTT: Yes.

MS WEST: So I've been on that probably for 12 months now. I actually think that's a very good model for funding. You have clearly outlined schedules as to what the individualised support package will provide. So it's sort of made clear at the front that it can be used for your attendant care or your district nursing or purchasing of medical equipment. So the issue that the paper has brought up here in terms of what will individualised support packages cover, they've sort of addressed that already at the front end in terms of even when you first receive the individualised support package. It was made clear at the start as to what it will provide. It wouldn't provide income. Income was certainly separate. It wouldn't cover sort of like hospital costs or anything like that. It was definitely made clear that it was just for sort of support provision and for equipment.

MS SCOTT: Okay, thank you. I'll make this my last question, so unless John has thought of some more this might be it. Just going back to your compensation proposal, we'll have to study this a lot more and thank you for providing material you've already provided. But I've understood that a lot of court cases never actually get to court; you know, compensation cases don't get to court. You might have years of waiting and solicitors working on your case and then of course you get out-of-court settlements. Does your argument about rebalancing, being able to voice your grievance and so on and justice - do you think that is dissipated in any way if in fact a lot of cases don't get to court, that they are one insurance company dealing with your lawyers and reaching an out-of-court settlement?

MS WEST: Maybe to some extent. But I think an individual at least - you know, if they really wanted to pursue it and really wanted to go through the court process and have the ability to negotiate the claim and to state their experiences and to achieve that - not achieve, but to have that responsibility assigned, I think at least they have the avenue to go through the court even if it doesn't reach the court and it is sort of resolved in the settlement phase. At least they're pursuing that pathway. On an individual basis they might feel as if some responsibility has been assigned or some blame has been attributed.

MS SCOTT: Yes.

MS WEST: So okay, maybe they don't actually go through the court case of sitting in court in front of the judicial or whatever and arguing the case. Possibly even though it's getting settlement there is negotiations happening behind the scenes, they are having to sit there and speak with the legal team and legal action and it is being negotiated and they do have an opportunity to appeal or to sort of push the banner if they feel like it on an individual level. So I think it still does provide that opportunity and that scope if you have that pathway available.

MS SCOTT: Yes, I understand, thank you. John, are you finished?

MS WEST: Thank you, Raelene. That was very interesting.

MR WALSH: Thank you.

MS SCOTT: Thanks, Raelene. We are now going to stop for lunch. We are going to resume promptly at 1.30, so see you then. Thank you.

(Luncheon adjournment)

MS SCOTT: Well, we might resume our hearings now. We're going to be hearing from Youth Disability Advocacy Service. So George and Jess, if you'd like to talk about your proposals and your ideas. If you guys could identify your role and your organisation that would be good.

DR TALEPOROS (YDAS): I'm George Taleporos. I'm the manager of the Youth Disability Advocacy Service.

MS KAPUSCINSKI-EVANS (YDAS): I'm Jess Evans and I'm part of the steering committee.

DR TALEPOROS (YDAS): And Jess is going to speak about our opening statement.

MS SCOTT: Okay, thank you.

MR KALISCH: Thank you.

MS KAPUSCINSKI-EVANS (YDAS): To the Productivity Commission. The Youth Disability Advocacy Service or YDAS is a Victoria-wide advocacy service of the Youth Affairs Council of Victoria funded by the Victorian parliament to provide individual and systemic advocacy for young people with disabilities between 12 and 25 years of age.

A long-term care and support scheme is a necessary entitlement for people with disabilities in Australia. Such a scheme is desperately needed to enable people with disabilities to contribute as active and valued citizens and facilitate full economic, social and cultural participation. Providing timely ongoing individualised support across the life span of a person with a disability would address the significant disadvantages, inequality and unmet need that exist in the current system. The guaranteed provision of personalised consumer-controlled support would contribute to a much needed and vital sense of empowerment, control, personal security for people with disabilities and our families and carers.

Who should be eligible? The scheme should be available to all people who are born with a disability or acquire a disability before the age of 65, regardless of the cause of disability. Support should be available across an individual's life span, continuing to meet that person's needs as they age. Lifelong eligibility for support under the scheme would help promote continuity and enable successful life transitions. Eligibility should not take into account people's income and assets. Means-testing would create a barrier and disincentive to participation in the workforce. Many young people with disabilities, like other young people, view employment as an important part of their lives and may aspire to achieve success in their chosen careers. Means-testing of the support scheme will result in a perverse conundrum for people with disabilities who will fear losing their supports if they earn a decent income and become successful in their careers. The scheme should be available to all those living with a disability, not just people born after a given date.

How the funding should be administered. Support provided to people with disabilities should be flexible, individualised and allow for maximum consumer choice and control. Funding administration options should include the full spectrum of control to enable people with disabilities to access the level of assistance and/or independent management of funding that they desire. Options should include a financial intermediary model as well as direct payments where people with disabilities can have maximum control over their own funding and service arrangements. Direct payments should not be considered as income by the Australian Tax Office.

Where people wish to take maximum control over their funding and supports they should have available assistance and information necessary to enable them to do so. Accountability guidelines need to be clear and accessible and not onerous. Appropriate support with respect to accountability processes also needs to be available. These things will be necessary to enable the successful operation of the varied funding arrangements.

Access to services and resources under the scheme should be driven by the individual needs and choices of people with disabilities. As informed consumers people with disabilities should be able to choose and direct their services and supports to take into account individual needs, goals, aspirations and lifestyle choices. Enabling people with disabilities to exercise choice and control over the services and supports they choose would provide a significant incentive for service providers to offer a greater variety of better quality services.

The nature of the services. Reflecting the generally broad impact of disability on a person's life, the range of services provided within a long-term care and support scheme should also be comprehensive, including aids and equipment, personal care, leisure and recreation, home and vehicle modifications, assistance with transport, employment support, sexuality and human relationships, support for life-long learning and counselling, advocacy and mentorship.

Assessment. The assessment for support under the scheme should not be unnecessarily intrusive or repetitive. Where a condition is expected to remain stable, assessment should not need to be repeated unless an individual acknowledges changes to their needs or circumstances. People should be able to request reassessment if they have a change in their life circumstances or to facilitate a life transition. Where an individual's disability may undergo change, degeneration or improvement, reassessments and reviews should be available as needed. Implementation of these necessary changes to support should occur in a timely manner. There needs to be an accessible and effective appeals process available to all those who undergo assessment and review. Assessments and reviews should be carried out by disability-trained professionals who have an understanding the whole of life aspect of disability. They should not be carried out by GPs.

Workforce issues. Young people with disabilities have raised a number of issues related to the characteristics of the disability workforce. These include the importance of being able to access support from people who they can relate to and feel comfortable with, therefore, many have a preference for support workers who are of a similar age to themselves. More needs to be done to attract younger workers to the field of disability support. Formal qualifications should not be a prerequisite for people to work in the industry. Positive attitudes towards people with a disability should bear greatest weight in choosing candidates to work in the disability field. Being able to decide who provides personal support should be seen as a fundamental right of a person with a disability who has direct support needs. Individualised funding with the option of direct employment arrangements are necessary for young people with disabilities to have maximum control over who provides their support.

YDAS would like to thank the federal government and the Productivity Commission for the opportunity to discuss the needs an interests of young people with disabilities in the context of a lifetime care and support scheme. Thank you.

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

MR WALSH: Yes, thanks Patricia and thanks Jess and George. I just want to start off with a question - I think the way you articulated effectively those principles was very useful and positive. My question relates to the role of the person with the disability in deciding the qualifications and qualities required for a care worker or other person who (inaudible) personal care (inaudible) for example (inaudible) if something goes wrong or there's misinterpretation of needs or other issues. So it's a question of practical application of those principles, I suppose.

MS KAPUSCINSKI-EVANS (YDAS): Is it all right if I - yes?

MS SCOTT: Yes, please.

MS KAPUSCINSKI-EVANS (YDAS): I guess my response to that would be firstly, that even with private employment that does sometimes exist there are government measures already in place to ensure that people are covered for things like that. The system we're proposing also doesn't exclude the role of a carer agency and they would have their own policies et cetera. Also, I suppose, the general understanding is that if you have a support worker who you like and who you trust, the agreements as to what they are and are not allowed to do are already clearly set out before they even start - sorry.

DR TALEPOROS (YDAS): To answer the question, I just think that for a long time the whole issue of risk aversion and wanting to control the lives of people with disabilities is what has gotten in the way of people with disabilities living the lives of their choosing and having choices and freedoms. I know that proposals around the Victorian direct employment scheme means that there will be opportunities for services to access WorkCover and those sorts of schemes. Obviously there might be need for support, as we mentioned in our paper, for people with disabilities who want to - directly employed to understand what the rules and what the regulations are around employing people. So I really do believe that if people are provided with the information and training that they can make informed decisions. Often it means that people can come up with arrangements that are suited to their individual needs instead of blanket rules that often restrict them.

MR WALSH: Okay, thank you.

MR KALISCH: So George and Jess, you're suggesting that there are ways in which a scheme can deal with these issues in terms of having people with the right attitudes and perspectives in working with people with disabilities as well as having some of the professional needs catered for in accommodating ways?

MS KAPUSCINSKI-EVANS (YDAS): Yes. I mean there's nothing to say that you can't employ, for instance, someone who has had official disability training but certainly it has been my experience that some of the carers I have had with that qualification have actually been worse than the ones without it, paradoxically, because it is that sort of desire and already sort of being imbued with some sort of - - -

DR TALEPOROS (YDAS): Yes.

MS KAPUSCINSKI-EVANS (YDAS): Yes.

DR TALEPOROS (YDAS): I would support that in the work that we've done that we've had lots of young people say to us, "That we are very - as young people we're very good at knowing who is suitable, who has got the right attitudes. We want the control and the ability to make choices around who supports us." I think that's a real fundamental right which I would home this scheme would allow for.

MS KAPUSCINSKI-EVANS (YDAS): I mean the other thing is that as a person who employs carers I don't think we've ever had situations where we haven't done our utmost to train people effectively such that they don't hurt themselves on the job but also looking after my best needs as well. I would be surprised if there were many people with disabilities who would sort of feel like they had ever deliberately put a carer in a situation that they were not able to deal with effectively.

MR WALSH: Would you almost make it a condition of having individual funding and employment responsibilities that the person with the disability undergo some training in this area?

MS KAPUSCINSKI-EVANS (YDAS): Potentially.

DR TALEPOROS (YDAS): Yes, and I think that then I would like the scheme to have an individualised approach. There are a lot of people with disabilities out there who already to run their own businesses and they understand what's required. There are others who don't and that will need that training and support. So it's about not having blanket rules but understanding that there is need for training and support for some people and for others they might be able to go ahead and do it quite well and successfully.

MS KAPUSCINSKI-EVANS (YDAS): I mean the other thing is that in terms of direct employment I think it's important to define that term because there are systems that sort of currently exist that do something similar. They don't necessarily refer to - well, I don't know. There's direct payment and there's direct employment, which are similar but not the same. So if a person with a disability wanted to, the extent of their control could be that they were able to fund their own things but that they could still choose to have their carers go through the normal protocols of training and working through an agency.

DR TALEPOROS (YDAS): I think there's a lot of work that has already been done in Victoria though the service and orientation unit at DHS that would provide the commission with some good foundations around models and learnings and also - they've run pilot projects and that might be a good place to start.

MS SCOTT: Thank you. Thanks for the suggestion. I mean I found your submission very clear and concise on the issues that you've identified, but one aspect I didn't see in your report to us at this stage is who you see controlling or delivering case management or something like that. You've got assessment by multidisciplinary teams, not GPs, you're employing people and you've got money going directly to you, and specified the range of services and so on, but what is the best view you think on who is the organisation controlling it? Do you have any views on that?

DR TALEPOROS (YDAS): In terms of your question, who is the organisation controlling it, I think that's part of the problem at the moment. I think there's too much control by organisations who are run by people who don't understand necessarily what they need. I think if there's an appropriate assessment done and that assessment identifies the full range of needs, I need to emphasise that the current system doesn't do that. I know that a lot of clients that we work for are very, very much under-serviced, don't have the funding they need. I know that Jess and Liz can speak for themselves, and also myself, if our family and informal support wasn't there, we would be in dire straits. But to answer your question it's really - for consumer control to exist we need to step away from that thinking that says another external organisation controls it.

MS KAPUSCINSKI-EVANS (YDAS): I wanted to come back to that term "case management" because in my circumstance, my mum is my case manager and I mean that in a very literal sense that she's the one that liaises with agencies and carers and with the funding bodies. There are many examples of that similar situation. I'm not saying that's ideal but I'm saying that there are instances where having a formal case manager can actually be more of a hindrance than a help.

MS ELLIS (YDAS): I'm sorry I was late, my apologies. I'm Liz. I would also like to add to that in that while I don't particularly need case management I'm it, and people don't understand that. But I would also in that that if we're talking about people needing to do assessments better than they are able to do now we need to really make it a prerequisite that they have a creative writing course involved in their writing because as you know in allocating the funding, people would read a million things on the same thing and they have to differentiate between whose is better pretty much. That comes down to the way you write it. I've seen some things that make me look at my life really negatively and you want to see something that actually makes you see a holistic, positive picture, and that comes down to the people we employ that are writing things on our behalf, because I can feed them the same thing time and time again. I've had to go through the process three times at the moment and it doesn't reflect me. It reflects a version of me, not me as a person.

DR TALEPOROS (YDAS): That's because of the (indistinct) situation at the moment. We're putting funding into the wrong areas, as I think we heard earlier today, from Val. Instead of giving the funding to the person, we're funding case managers and planners. I'm not saying there's anything wrong with those roles but unfortunately they spend so much time, and even occupational therapists writing submissions over and over again that kept getting knocked back. It means that funding is being spent on their hours but it's not being delivered and if we had a scheme that was really around entitlement that was holistic and that looked at what the person's needs are and funded it, then we wouldn't have to fund these unnecessary creative writing people.

MS SCOTT: You see the assessments going to an organisation and the funding, let's say it's done by the Commonwealth. You see the organisation that gets the assessments then determining funding that is then given to the individual. Who is doing that bit in the middle? Who's the organisation that's getting the assessments and making the allocation of funding to the individuals? Would you like it to be DHS in Victoria? Would you like it to be a non-profit organisation? Would you like it to be Centrelink? Would you like it to be the TAC? Would you like it to be a new body? Have you given any thought to who you would like to see as that body allocating the funds?

MS KAPUSCINSKI-EVANS (YDAS): I had a proposal actually. This is going to sound incredibly nerdy so I apologise, but one of my friends is studying politics at university and she had an assignment to create a policy proposal and hers was an actual stand-alone department for disability affairs, much the same as indigenous affairs. In principle that's not bad because it would do exactly what this insurance scheme does and say, "Okay, this is a person who has a disability and who will do this, this and this potentially throughout their life and who will need this, this and this in order to do that, and so we will do our utmost to enable them to do those things." I mean that's possibly a bit of a stretch, you know. It's possibly an ideal world scenario. The principle of what DHS does is good but there would need to be changes in the execution, I suppose.

DR TALEPOROS (YDAS): It might be about people having a choice of different organisations. Sometimes certain ways of doing things develop that aren't necessarily in the interests of people with disabilities. My preference would be that there is almost no middleman unless it's necessary. If people need the middleman then the middleman comes in, but if people are able to get on with life with their funding allocation and make choices around how the funding is used - and if we're talking about sustainability of a service we need to not start creating future bureaucracies around how they're administered.

MR KALISCH: I have one question about your experience with the educational sector. Given your age you've got greater recency of experience with the education system. Would there be other suggestions or arrangements that you'd suggest be put in place to make the education system more accommodating?

MS KAPUSCINSKI-EVANS (YDAS): I guess the state government who fund pre-tertiary education, they actually fund the provision of a single person who can perform educational and personal care type support. That seems to me the most efficient use of resources and stuff. That is funded by the Education Department rather than DHS. I would be in favour of something like that, particularly because - you know, this is not by any means the final model but a lot of universities have, despite what they claim, money to throw around and they don't always throw it around effectively and to the right places. I think this could be another example of universities being more inclusive.

DR TALEPOROS (YDAS): I think it's important that the Productivity Commission, in proposing this, understands that the Education Department, particularly at the tertiary level, is not providing the support that people need to either attend TAFE or university or vocational support. There's a void at the moment. If we're really serious about the whole of life of people with disabilities we need to support them in whatever course they take.

MS KAPUSCINSKI-EVANS (YDAS): It has been raised, when talking about those issues, that you get that support at university but then what do you do when you want to go into the workforce. Look, to be honest, I don't have the answers to that either but it is possible that again from the Department of Education and Training there should be some assistance as well, perhaps in addition to the insurance scheme.

DR TALEPOROS (YDAS): We also need to recognise that the current support provided in the workforce often doesn't extend to personal care. There's a limit of 10 hours of personal care within the workforce. That's too low and it doesn't cover high support needs.

MS KAPUSCINSKI-EVANS (YDAS): I actually would like to professionally write and direct theatre or maybe even film and TV, and that must be a government's nightmare because the hours are much longer than 9.00 to 5.00 potentially, but it's what I want to do and I want to be assisted to do that.

DR TALEPOROS (YDAS): Young people are really saying that, you know, they want an education, they want to work, they want lives. We're really happy that this will be a door for that.

MS SCOTT: John, have you got any more questions?

MR WALSH: Not really, Patricia. I think you've already answered these questions but probably David's last question around the education system, the support in transition from the education system to the workforce is something that we're interested in obviously, and I think you observed that that's inadequate. Is that a fair reflection of what you've said.

MS KAPUSCINSKI-EVANS (YDAS): Yes.

DR TALEPOROS (YDAS): Yes, it is, and particularly for people with higher personal support needs; it is. I mean, there will be funding for workplace modifications and that's good and necessary and helpful, but for someone like myself or Jess or Liz that need personal care support, the caps and the limits make it extremely difficult. So what do we do, we fall back on DHS, and DHS says there's no funding. So sometimes we might be out of work or not be in a position to get jobs. We know that the workforce is such an important - not just for finances socially, emotionally and contributing to our community.

MS KAPUSCINSKI-EVANS (YDAS): I mean, also you could argue that the government would like more people in the workforce to strengthen our economy and all that stuff.

MR WALSH: What about finding work in the first place, is there any support?

MS ELLIS (YDAS): Can I say that I find the employment system very, very frustrating and very demeaning. The mere fact that because you have a disability and need more support in the workplace that you have to go to a disability employment network, even if you don't need the type of assistance that they provide, that's how you get the funding, it's how you access the funding to get the support, that needs to be scrapped because people don't understand that. I've had to tell them where to get the funding from. How I did that was I actually went to George and said, "Where do I get the information for this from?" That needs to be scrapped. I don't believe that people who don't need it need to go somewhere every fortnight where they say, "How are you going with your work? What are you doing?" I don't need that. I have the ability and capabilities to get a professional degree. Why do I need somebody else checking up on my work? I found that incredibly frustrating.

I think a lot of this comes down to the fact - and was identified in the issues paper - that we have a fragmented system. You've got to go to different places for different funding and then navigate it and help the department to understand what funding you're talking about because every time you make a phone call you get somebody that doesn't know what you're referring to because the systems are very hidden within the department. I think if we could streamline it a bit better so you weren't having to justify yourself all the time to a number of different places it would help us dramatically.

MS KAPUSCINSKI-EVANS (YDAS): Can I also add - I'm sure you love vague symbolism - that one of the problems that I am certain that I will have to face, particularly in the creative industry, is stigma, but I mean it's not limited to that industry. The mere fact that you have a disability prevents you from being employed because people feel that you won't be able to do an effective job. I've been lucky enough so far to come across people who haven't had that opinion and who have been really supportive of my work but I'm not in the real world yet.

DR TALEPOROS (YDAS): I really agree with what Liz has said that the current system is set up assuming that people (indistinct) a certain way and can't get jobs because they don't know how to write their resumes or this and that. The reality is that there's a large group of people with disabilities who have high support needs and all they need is that support in the workplace. That's not currently offered or available. Furthermore, if you put that in your DHS disability support register application no-one is going to look at it because you've got other people who don't have the very basic needs to get out of bed in the morning. We're too much in a position of dealing with the very basics. Employment and education doesn't get a look at and it should.

MS ELLIS (YDAS): It's terrible to think - and I was thinking about it again this morning - we all may have disabilities and have a level of support, but we're all in competition with each other for the same basic needs and that doesn't work because you think, "This person's got that but I want that too," and you shouldn't be feeling jealousy or anything towards that person because we all should be entitled to the same things. You think, "Oh, but they got it so when is my turn for this?" It shouldn't be like that for anyone, and hopefully for other generations to come. One thing I would like to add - and I do apologise for my lateness - I read in our submission no means testing on income, that sort of paragraph. I'd also like to say, as a person that is technically only a young person for another year under the government, I don't think that there should be any means testing for anyone with a disability because regardless of my age, my financial situation will not change.

Just because my parents have always chosen to go out and work - and effectively my own mother is a single mother, she changed the structure of her work environment when I finished high school and there was no support available - why are you being judged on what your family has and how they have chosen to be able to provide for you. It should be based on you, and the needs that you have should not be justified on what you earn and therefore can provide for yourself. If I was spending that money on paying a support worker there would be none left for me at all. So I really do think that that's a very important point to emphasise because you're just going to create more fragmentation between families and the ones that go out and work and the ones that try and push their children to want the same thing and that's not fair. Everybody has got their talents and everybody is entitled to use them. As a society and as a community we should want that.

MS SCOTT: Thank you very much. I wonder if I can encourage you, given that you've already written such a good submission already, to particularly focus on education and employment transitions because there won't be necessarily a lot of groups out there that will have your insights that would necessarily address that. The other one, just as a lingering question for me, George - I know you said that you'd like a really streamlined model - the scheme is going to be extensive and covering a lot of people. There probably will have to be somebody, some organisation, doing a little bit of coordination and I guess if you could have a view about who that is, even if there's no-one in the middle, you might want to comment on the arrangements at the top. That would be helpful as well. So I guess encouragement to say something more about education and employment and the organisation, that would be most welcome. Thank you very much.

MR KALISCH: Thank you.

MS SCOTT: I think we have now got Vern Hughes. Just before Vern comes forward, is there anyone from the press that has joined us? We have a few guidelines for press people. No no-one from the press? Thank you. Vern, welcome to the table. If you'd like to identify yourself for the transcript and your role and your organisation, please. You might want to commence with a short opening statement, and then we could ask some questions of you.

MR HUGHES (NFFPC): Thank you. My name is Vern Hughes, the secretary of the National Federation of Parents, Families and Carers. That's a body of 1200 parents and family members, principally with a family member with a disability or a mental illness or a drug and alcohol addiction or a complex or chronic health illness. I'll make a few general comments about the issues paper, on some of the broad general framework that you're wanting to put up in order to think about alternative options for long-term care and support, and then I've got a couple of specific issues which deal with the specific questions that you've put up.

The first point is that a transformational change in disability funding is long overdue. Almost everybody says that transformational change is necessary, but not everyone means the same thing by that, and I think it's very important to be as clear as possible about what it is that's to be transformed. For us it's the provider-centred nature of our system that must be transformed. To be clear about this, it's three things: it's information, resources and decision-making that are centred in provider organisations, not in persons with a disability or their families.

Resources is clear, because funding goes to provider organisations; information is kept and only accepted by funders if those information systems are in provider organisations; and decision-making capacities of provider organisations are deemed in human services departments, education departments and health departments to be preferable to decision-making capacities of individuals and families. All of that has meant, for obvious reasons, a dysfunction disability system, because the provider organisations are - surprise, surprise - fragmented along disciplinary lines, sectoral lines and jurisdictional lines, which means that there's a plethora of agencies dealing with bits of persons, not with the whole person.

However, it's also very clear that part the reason why this inquiry is proceeding is that three large service providers, the Spastic Society, Disability Services Australia and Yooralla have lobbied for it. I think one would have to have rocks in their head to think that those provider organisations are going to give up their provider-centredness. They are not going to give up the power to hold resources, to hold information, to be gatekeepers to the system, to be sources of information about the disability system to someone else, they are just not going to do it.

In fact their aim is to become national providers rather than state based providers, and all of them have strategic plans which move in that direction. So a national scheme has a certain appeal for them because it means they are able to step into the role as a national organisation. Why is that important? I think if the aim is to move from a provider-centred system to a person-centred system, some of the proponents of change will not want a person-centred system. So we just have to be extremely wary about that and wary about the use of language, because I think one of the things that will inevitably happen in this process, as happens in all political processes, is that the language will change to accommodate what everyone wants and not everyone will mean the same things by the same language. They are some general observations.

A couple of others. At several points in the issues paper I think there are some assumptions about family carers that are problematic. This is not developed at great length in the issues paper, but nevertheless in the discussion around it I think there is an assumption that reliance on the part of people with disabilities or on family carers is something that is unsustainable, the number of family carers who will want to do that is dropping right away, and therefore there needs to be a kind of shift from informal unpaid care towards formal care by organisations.

There is a kind of assumption that sits through the issues paper that we need to accelerate that shift so that more of the care is done in formal organisational settings rather than in informal familial settings. I think that's a wrong road. Most of the people who are presently reliant upon families for a large part of their support or families who are caring for a person for a large degree of their time don't want to substitute informal arrangements for formal organisational arrangements. What they want is to be able to have supports that are tailored as much as possibly to their actual individual needs.

It is a worry that the fact that many family carers are aging is sometimes put up as a reason why we have to move right away from the idea that informal care is not sustainable. There was a bit of a discussion in the last little bit of the previous time about employment issues. Again I think there's a bit of an assumption in the issues paper, at least behind it, in that governments will be very interested in an alternative scheme if it's likely to reduce the number of people with disabilities who are unemployed and on welfare and we'll see more of them in the workforce. Some of that discussion comes with a bit of language about the use of incentives; that a manager of some kind will have incentives to get more people with disabilities into the workforce. I think there's a lot of naivety in those assumptions.

Many people with capacities to be in the paid workforce work very hard looking for employment and I don't think any fund manager with incentives is going to make much of a difference to them. What would make a difference is the provision of incentives to employers. That's in a sense something that you can do quite independently of how you organise and fund the disability support system. I mean, providing incentives to employers is a quite simple to do. I will come back to the more general questions about whether a long-term funding system should be an insurance model or not an insurance model.

The reasons for thinking that it might be better to do that as an insurance model seem to be twofold. One is that there seems to be an argument that if you can fully-fund a person's support entitlements over the course of their lifetime, that's better than if you do it on a year-by-year basis. I don't know why that's better. If a 20-year-old has 60 years ahead of them and has X, Y, Z support needs, then you can do the sums and add up X amount of dollars by 60 years and get to a certain amount of money and you can try and fully-fund that amount of money up front. But why? What's the point of doing that? We don't do that in the general health system. We don't do it in the social security system. We could.

Other countries in the world do. But we don't. There might be a case for doing it in disability, but I have yet to hear it, and perhaps during the course of this process over the next year we might tease out what that is. But I don't immediately see that there is any intrinsic value in trying to bring together a great big bucket of money which says, "This is what you're going to be dipping into over the next 50 years of your life." It seems to me an unnecessary financial pressure on bringing a whole lot of resourcing up-front so you can then call that an insurance system rather a year-by-year payment system.

The other reason why an insurance system seems to be thought better than a pay-as-you-go year-by-year system is that whoever it who manages the bucket of money that's set aside for your lifelong support is given an incentive to manage it so that they reduce the long-term spend. Again it's not clear to me what advantages really follow from that, short of trying to push people into an employed role rather than one where one is in receipt of, say, a Disability Support Pension. It's not clear to me what the advantage of that is because I'm not sure that a fund manager can do very much with the incentive idea in front of them, where they're going to want a person particularly to do these kinds of things rather than these kinds of thing, because at the end of the day I don't think a fund manager can or should have that much influence.

The emphasis should be on self-management, self-care, self-direction for people, so that, yes, people ought to be able to be looking at continually finding ways of doing things better and continually finding ways to enhance abilities in all kinds of areas. But everyone has a personal interest in doing that all of the time. I wouldn't place much store in giving that incentive to a fund manager. They're my general observations. A couple of very quick specific points, because I don't want to take up too much time. Question 3 in the issues paper talks about who should be the focus of a new scheme, questions here about assessing need and how it's possible to build a system of entitlements around different degrees of need.

It's important that the question is asked because it is an important one, but I think I would be very wary of a scheme in which an organisation that has responsibility for managing a pot of money is the same entity that determines need. So if you have an insurer who manages a big pot of money and that same organisation is the one that determines what your need is and how much support you have compared to someone else, I think that is a recipe for a lot if dissatisfaction. I think that the two functions need to be separated out so that there is an independent determination of need and eligibility and then there is a fund-management role; but combining the two, not a good idea.

Who makes decisions? Again I think it's very important to separate the question of fund-holding, holding the money, managing the money, from the role of being a service provider. Part of the root cause of the dysfunction in the system at the moment is that providers do both of these things: they hold the money, they are sources of information about the money and what is available, and at the same time they are providers of services about how the money can be spent. It's just an impossible conflict of interest that service providers hold. So pulling those things apart I think is essential.

That doesn't mean service providers don't have a role. I think they will have a continuing role as a supplier of specialist knowledge and expertise about particular kinds of services, whether it's to do with deafness or whether it's to do with acquired brain injury, and the management of specific issues there. There is a role for organisations that have specific expertise, but service providers should not fund holders, they should not be sources of information about the system, they should not be suppliers of information to people about what is out there.

I think one of the things that is needed in moving away from that kind of provider-centred system is an independent source of information, independent of providers, perhaps as a statutory authority, that has the capacity to say, "Here is our range of providers. This is what they provide, for this price, and this is what we assess their quality to be," and I would give that authority the power to find that information, publicise it on a web site at arm's length from service providers. We don't have anything like that at the moment.

If you go to a service provider at the moment and ask, "Can you recommend a school that would fit a 12-year-old with autism?" they will say, "We can't make any recommendations to you of course, but you might like to try this one and you might like to try that one," and that's if you're lucky. Often they will just say, "No, we can't help you, because we're not in the business of making recommendations like this." But it's the thing people most want to know. It's a huge hole in the system at the moment.

On the question of who should hold and manage money, my view is that a person with a disability and/or their family should be able to nominate an agent who would hold the money on their behalf, and there's really no limits as to what that agent could be: it could be a GP, it could be a family friend, it could be a community health centre, it could be a health fund, it could be any kind of community organisation that you have confidence in. There's no reason why that needs to be restricted to a specific set of organisations which have the word "Disability" in front of their name.

Just a point on workforce issues. My view here is that of the people that I know personally who employ support workers, either as people with disabilities selecting and appointing people themselves or families doing that on behalf of a family member, almost all of them have a policy of avoiding people trained in the disability system, and they do that because they don't want people who have learnt to think in a kind of disability mode of thinking.

Often those people will say, "Look, I've had some disability-trained people as support workers, but I've actually gone recently into employing an African woman who is an overseas student. She knows nothing about disabilities, but she is fantastic because she doesn't have disability blinkers, she just encounters the world and the person as she sees it." So the idea of there being a disability-trained workforce that's important to a company, the journey of people into the community, I think is somewhat misguided.

MS SCOTT: Vern, I just wonder whether we should stop there - - -

MR HUGHES (NFFPC): I'll stop now.

MS SCOTT: - - - because we have got some questions. It might be the case that if we run a little bit over our time, Vern, we'll just shorten afternoon tea. So we'll just see how we go. Look, I might lead off this time, if my colleagues don't mind. I want to come back to one of your first statements, which was that your federation very much wants to see the family at the centre and was a bit disturbed by what was in the issues paper. We have heard, of course, the contrary view, from a number of people who have talked about demographic concerns that they've got that they're ageing, their child is ageing, who needs assistance, and that there's this time bomb out there and it's all going to collapse in a crisis. We've even heard from some officials who have talked about how they'll cope or not cope with demands on care, respite care and so on.

So I guess my question to you, short question to you, is how long do you think you or your federation members think they can care for their dependent children, if they are dependent, and what systems do you think will be existing in the community to provide the care you think that they need after you've gone?

MR HUGHES (NFFPC): The issue is that support arrangements should be tailored as much as possible to the individual needs of every person. Everyone's situation will vary greatly. Some people are without a family, some people have a family but don't want to have a close care or support relationship with them, some people have a family but have had a negative experience finding the family influence was too restrictive on their development. But still, 91 per cent of people with disabilities are entirely reliant upon their families for accommodation, food, clothing and shelter.

So the question of enhancing support for people with disabilities is in very large part a question of how to enhance the capacity of families to provide support and care in a way that's sustainable. It's not about removing the function and putting people in a small-I institution. Almost no families want that and almost no people with disabilities want it. The question is how to enable support to continue to take place in home, community settings that look as much like ordinary life as possible and how to enable the supports to come to the person's home, to come to the places where people live on a day to day basis rather than trying to fit people into systems and respite arrangements and accommodation services that exist independent of the people who they're intended for.

MS SCOTT: That 91 per cent figure, that would predominantly relate to situations where it's parents and their dependent child, I imagine. Have I got that right?

MR HUGHES (NFFPC): In most cases, but not exclusive, because there are a lot of siblings who, as siblings, provide care.

MS SCOTT: Okay. But because people are living longer and families have had considerable responsibilities for 40 or 50 years of care, I just need to say to you that we've heard lots and lots of stories already - even at this early stage received submissions where people are saying they can't continue the care and they can't see necessarily other family members being able to step in. So I just want to have some understanding of, either in your individuals cases or the members of your federation, how you see the family continuing this in 30 years time when - you know, 40 years time when we're not necessarily going to be around.

MR HUGHES (NFFPC): The solution is not to put people in institutions. Let me tell you what our solution is. I have a cousin who lives in a small Victorian town, about 2000 people, has a combination of intellectual disability and autism and for many years lived with his parents who died about five years ago, both of them. Since then this person now aged about 45 continues to live in the family home in the same town and has a very well developed network of neighbours, extended family people, friends, sporting club people who come through the house many times a day, look after him, keep an eye on him. But, you know, he can manage, he can cook and shop and pay bills with the assistance of other people. If at the point when his parents died that person had been shunted off to another town with a group of strangers and stuck in some kind of institution, he would have died. He would have died within a year. So yes, there is an issue of what happens when parents die but that must not be an excuse for sticking people into formal care where they are dependent upon the will of strangers who they don't like and don't want to spend their lives with.

MS SCOTT: Okay.

MR KALISCH: I think the issue you raised is one that we're certainly alert to in terms of - I mean there are not just the two extremes of familial care and institutional care. There are many sort of forms of care and packages of care and arrangements in the community, arrangements with informal carers. Just picking up on what Patricia said, I suppose the sense we're hearing from a number of family carers - and your organisation may be in a different situation, I just want to test this out. The sense we're hearing from a number of family carers is that the expectation on families in the current system is too great; that it's not a sense of saying to families, "You don't do - - -"

MR HUGHES (NFFPC): Of course it's too great.

MR KALISCH: - - any caring." But the sense that we're hearing from families is that the expectation on them is just too severe. It's too great and that they would like some rebalancing in terms of their own responsibilities - and most families say, "Yes, we want to keep caring, we want to keep contributing, but we don't want to be the only source of care or the 95 per cent source of care and support for our child," and draw on some funded services, some respite, some other things to actually rebalance their arrangements. I mean is that something you would support?

MR HUGHES (NFFPC): That's exactly what I'm saying.

MR KALISCH: Okay.

MR HUGHES (NFFPC): Most of those families will say that most of the support services currently available are of no use to them. The respite, for instance, is usually too inflexible, too centre based, not enough flexibly oriented to the home of the person concerned. So many families will say, "Look, I'm desperate for respite but I'm not going to bring in some stranger who my son or daughter doesn't know and doesn't like." Often agencies that provide respite scratch their heads and wonder why people don't come and use their services. Hello, people don't like spending an evening with a complete stranger who they're not going to see again the next day or forever more. I don't. It's not rocket science why people don't use many of the existing services that are available, because they're not personally attuned to the purpose they're supposed to be for. So of course most people who are in a caring role want to have a more balanced life. They want to build in personally-tailored supports here and there so that their role is easier. But it's very difficult to do that because most services are not in a form that you can tailor very well.

MR KALISCH: So is that where you see some benefit or opportunity in more of a package-type approach where people have greater choice in the services and supports that they can purchase and if something doesn't suit them that they can divert those resources to other forms of support or other providers?

MR HUGHES (NFFPC): Of course, yes. I think it's - what that leads to, I think, in funding arrangements is much more to a system of entitlement for people to - for a bucket of money. For some purposes you might have reasonably tight guidelines as to what the money might be spent on, for other things it might be very light and very open; but with a bucket of money where some real choice can be made. Choice at the moment for most services usually means, "We can provide you with this and this, with these people at these times. Is that okay?" But you never see the money and you never know what things actually cost.

MR KALISCH: Can I just go to one aspect of the funding that you talked about in terms of pay as you go. Certainly one of the aspects that has been raised with us about one of the benefits of having a fully-funded system is actually the opportunity for a new scheme, whoever it is managed by, to actually invest effectively and intensively in early intervention services. Certainly the sense that has been sort of given to us is that only a fully-funded sort of up-front funding will actually more than likely provide you with the funding capability to actually make that early investment, whereas pay as you go is more likely to sort of stretch the funding across multiple needs. Is that something that you think of?

MR HUGHES (NFFPC): No, I think most families have the experience that there's an enormous amount of early intervention that could be done with existing funding arrangements but which mostly doesn't happen. So to give the example of education, because you asked a number of questions about education, many families that have a child in the education system and who receive a funding entitlement for an aide but which goes to the school have a complaint that they can't really use that money for the things that really fit their own child. Education Department say, "It's our money. It might be tagged for your child but we will spend it on what we think is fit," even when the family will say, "Okay, there's $18,000 there. We, the family, will supplement that 18,000 with our own 18,000, making a total of 36,000 a year, to which we could do something really useful with." Education Department will still say, "No, we won't allow you to top up that amount with your own contribution." You could do that in a very serious way with some early intervention goals. You could begin to sort of address the educational deficits that people have with a real amount of money and get stuck into it for a year.

There are many things of that kind that could be done already but where departments and institutions are dead against it because they lose - you know, they don't want to give up the control that they have. My problem with the argument that a fund manager then has incentives to do early intervention arrangements - my problem with that is that in the real world the fund managers are the same sort of people who run education departments.

MS SCOTT: Is that your experience in Victoria?

MR HUGHES (NFFPC):   They're just the same sort of people, really.

MS SCOTT: Is that your - I mean you might not have - - -

MR HUGHES (NFFPC):   Yes, so that they will think in the same ways, they will hold money, they will be wary of letting it go for things that they regard as a bit too creative or idiosyncratic. They will always want to sort of put people into a box because it's administratively more efficient. So I'm just very sceptical about claims that a bucket of up-front money will lead to better decisions about how it can be spent in ways that really work for an individual.

MR KALISCH: Yes. We heard something yesterday at one of our hearings in Hobart around a family which had a child with autism spectrum disorder. I suppose their main concern was that currently - the current system in Tasmania, it might be different in Victoria - but the current system in Tasmania is funded on a pay as you go basis; funding determined by government through the political process and that's the funding that's there and it's clearly inadequate to meet the needs of the child and of many other children in Tasmania, this person was contending. His proposition was that if you had a fully-funded system there would be resources available for early intervention services at the level and frequency that would actually make quite a difference to the child in terms of their education preparation which would have long-term benefits for them in terms of their life choices.

MR HUGHES (NFFPC):   But that would be the same for every child, including those without a disability. The Education Department at the moment could, if it wanted to, organise its funds so that every child, with our without disabilities, could have a personally tailored education environment. They don't do that and people with autism spectrum are the most disadvantaged by that at the moment.

MR KALISCH: I mean his contention was that by the time they get to sort of school age it's too late. You really have lost some of those opportunities in terms of brain development and plasticity of the brain, that you really do need to have a scheme in place before they hit the education system.

MR HUGHES (NFFPC):   Yes. My experience with two kids with autism and years before school is that it took about 30 assessments from early childhood intervention people to come to any consensus about what was happening. It was the age of seven that they finally agreed on a consensus. Are you asking me whether I have faith in those sort of people making an early, quick, decisive intervention at age two and then pouring a lot of money in to support a two-year-old, a three-year-old, four-year-old in the things that they really need at that point in a decisive, personally tailored fashion? That ain't going to happen because that's not how those kinds of people operate. I'm sorry, but - - -

MR KALISCH: No, that's all right.

MR HUGHES (NFFPC):   I'm sorry, but if you had a two-year-old and three-year-old, four-year-old who has done this and you've had battles with providers and social workers and psychologists who dither, put things off from one year to the next, do not make decisions, put it in the too-hard basket because the clock has just ticked over to 5 o'clock - do you expect me to say these people are going to make quick, decisive decisions in the interests of a child because they've got a big bundle of money they might spend? What I want is some reality in the discussion which takes account of human weaknesses, which is that human beings, especially in workplaces, are often lazy, often can't be bothered with things, will find easy solutions to things and where funding, as much as possible, is designed to remove those kinds of obstacles being in place.

So in my view if I were to do early intervention again, knowing my own child's experience, I would say yes, a bucket of money in those early years at the discretion of the family would be useful - - -

MR KALISCH: So that's the structure?

MR HUGHES (NFFPC):   - - - rather than having to go to 30 agencies without a consensus on what they think.

MR KALISCH: Okay. So that's the structure in terms of individualised funding: funding with the parents and the parents able to make some of those choices, working with professionals and others? Am I sort of understanding that correctly? I'm sort of thinking about in terms - - -

MR HUGHES (NFFPC):   Yes, yes.

MR KALISCH: I mean you've obviously had a difficult experience and I'm just thinking for others what can be improved in future, what structures and governance arrangements can make it better?

MR HUGHES (NFFPC):   I think allowing a bucket of money that is attached to a child to be used by the family, I think is the crucial thing. Whether you need an insurance scheme to augment the bucket of money you have or whether there's enough money already in there on a pay as you go basis, I think that's another matter.

MR KALISCH: Okay, thank you.

MS SCOTT: John, I think we've finished our questions here in Melbourne, but do you have some questions from Sydney for Vern?

MR WALSH: No, I don't think so, Patricia, because you and David have pretty much covered what I was interested in.

MS SCOTT: Okay, well, thank you. Well, thank you very much, Vern.

MR HUGHES (NFFPC): Okay, thanks.

MS SCOTT: Do we have Tom and Allen from Victorian Coalition of ABI Service Providers? Great, thank you. Well, we welcome Tom and Allen to the table. If you could just identify yourselves and your role your organisation, please, for the transcript, that will be great, and if you'd like to make an opening statement that would be good. Thank you.

MR WORSNOP (VCASP): I'm Tom Worsnop. I chair the Victorian Coalition of ABI Service Providers and I guess the perspective we want to bring today is the particular one around our experience in the ABI field.

MR MARTIN (VBIRA): My name is Allen Martin and I'm acting at the moment as the honorary secretary of VBIRA, the Victorian Brain Injury Recovery Association, which is an association of clinicians only who are active in rehabilitation work for those with acquired brain injury.

MR WORSNOP (VCASP): We haven't actually orchestrated our presentation.

MR MARTIN (VBIRA): One of the reasons for that is I think the coalition - we do have a lot of members who are involved across the spectrum and the coalition and ourselves - coalition was looking to us for some clinical support and we decided let's put it all together and come and see you.

MR WORSNOP (VCASP): So primarily the work that the ABI Service Provider Network does is around service provision, disability service provision, but it has, sort of as Allen said, some clinical work. But I guess our experience is really talking about some of the work that we're doing within the current disability system in Victoria. I guess some of the lead-off comments really are around the fact that the Victorian disability system existed prior to a lot of the work actually being developed specifically to target the needs of people with an ABI. So there has been sort of a history of the ABI sector trying to sort of carve a sort of a place within that that actually makes it more appropriately designed to deal with issues for people with an ABI. There are some learnings about that I think that we would like to be able to input it. It's early days here. We will be developing a proper written submission for it but I think just thought it would be good to sort of talk about some of these early issues anyway.

Some of the things, I think, that we need to talk about are really around rehabilitation as a core factor in disability response to people with an ABI. A system that's generally set up in a developmental way often misses some of the points around why it's important to have a rehabilitation framework in a disability system as well. A lot of that is to do with the fact that people start at a particularly - well, it's an acquired injury and people have had a regular life beforehand and life experience. Their injuries often then change the nature of their experience, quite significantly, in some cases. But that early memory and that experience of life beforehand is equally as important as life afterwards. There is a need to be able to look at the point beyond an injury where it's - people may be significantly injured but if you've got rehabilitation processes in place then people's needs will change rapidly according to good interventions. In some cases though that can be a lifetime experience and sometimes it can be a quick experience. I guess one of the key things that we'd be advocating for in this whole development of a new system is to recognise the need to be flexible around people's changing needs rather than locking people into a system which is assessed and diagnosed early and that sort of then informs the rest of people's lives. That's the sort of a starting point.

MR MARTIN (VBIRA): The situation which we're in is that the patients whom we are concerned with as having an acquired brain injury are today regarded universally as people with great potential. The head of Victoria's and possibly Australia's largest emergency accident hospital section in his Christmas message of 2006 talked about our - he'd just been all night treating an accident victim with a serious head injury. He came out and told the parents that the boy or young man had a severe acquired brain injury. The press were there and he turned to them and then said, "Two decades ago we would have just pulled the curtain across and said there's no hope. We don't do that now," and left it at that.

They don't do it now. Advances in medicine are phenomenal and over the last two or three decades Australia, by and large, has not kept up with the rest of the world, certainly not the rest of the world. I'm not talking just about America. I'm talking about small countries at times where the understanding of what acquired brain injury is and its breadth for mature people, I'm talking about, because this is something which is covered in Victoria by the Children's Hospital up to an age of 18 or even up to 20. If you take adults who have suddenly got an acquired brain injury and if I quote the Victorian government's or the Health Department's definition I would be reading:

> Acquired brain injury is not a mental illness and requires very different specialist skills from those offered by mental health services.

That's one of the confusions which the community has. It goes on with its definition as to what acquired brain injury is and the multiple causes of it.

We pick them up, who have been neglected by the system, partly because of the history but also in our multicultural environment we can't ignore the fact that when a young person or an adult even has had a stroke and has a brain injury, which is a real disability, is being told that this person is going to go to a nursing home because there's no place for that person to go because the state which has responsibility for rehabilitation does not have the facilities to cope with the numbers. Many, many of those without insurance, and 60 per cent of Australians haven't got private insurance, who aren't covered partly by schemes such as TAC or WorkCover, the family says, "We are a family." Their cultural commitment is to care and they won't send or allow the sending. This has happened for decades.

The result is now who is clogging up the nursing homes? In Victoria between 12 and 15 hundred nursing home beds are occupied by people who aren't 65 but are under 65 with an acquired brain injury. They might have other illnesses as well, many of them do, but these are real people who have had a life and now don't have a life unless helped. Rehabilitation is a word which hasn't come into our lexicon as far as medical care from hospitals and the community is concerned. This is a hidden injury. It's a real injury and it needs to be treated properly and adequately. Government and the community have responsibility in this area.

MS SCOTT: Could we ask some questions now? Would you be comfortable with that?

MR WORSNOP (VCASP): Yes, sure.

MS SCOTT: Given that you - would both of you have had exposure to people who are clients of the TAC here in Victoria as well as people who are not? You would have seen both clients, both of you?

MR WORSNOP (VCASP): Yes.

MS SCOTT: Are you able to make some comments about the level of support that those people receive, those who are in the TAC and those who are outside, because a number of people, including the report that was provided to the government before we got our terms of reference said that the level of care and support that TAC clients got was superior to everyone else. I just want to check if that's your experience. If you could talk about that for a few minutes I'd appreciate that. If that's not the case I'm happy to hear that as well. I just would like your view on that proposition.

MR WORSNOP (VCASP): I'll lead off. There's some - I think that the reality of the situation is that people who are recipients of TAC have significant and more resources that can actually address their needs than what people in the public system have. However, it's not always as clear as that's better or worse. Certainly a few years back the TAC recognised that one of the key problems going on with a lot of money was that people were getting significant amounts of attendant support that were babysitting them all day and all night. They then decided to pilot a case management system which wasn't existing in theirs which was available in the public system but rationed, and they found that then they were able to actually provide people with much better qualities of life because the services were more adequately directed. Also, I think that there was costs savings because of the fact that people didn't need 24 hour care, they just needed care when they needed it. It needed to be organised.

On the other hand I think there has been some conversation before about how financial systems drive the way in which services are delivered. Certainly our experience at the agency I work in, which did provide case management, there's a lot of demands on case managers, for example, to cut costs all the time when you've got a financially driven system. The public system is less inclined to do that, I think, in my experience in comparison. But I think equally there are problems around the public system not really recognising in disability services what I was talking about before about rehabilitation, whereas perhaps the TAC system has a much more strong emphasis on rehabilitation because it's seen that early intervention and rehabilitation services actually do make a difference to people's long-term care. So there's actually pros and cons and I think we will explore that a lot more in our - but Allen - - -

MR MARTIN (VBIRA): I think I should add just add that early rehabilitation - and the TAC has certainly improved its appreciation of that. But that might not be apparent for years. Those people have been occupying perhaps a nursing home bed. Their brains are still active in some areas. The ability of the brain to develop new connections - and we could give you scores of examples of people who have been regarded for a decade as having low response, declared to be totally without any signal of life who are now walking around, some of them in paid employment, others who are members of the community and active in it, because others have cared and been able to nurture and encourage that rehabilitation. It goes beyond the limits where TAC, despite its improving education, still hasn't got control over the knowledge about acquired brain injury that carers should have, as from that definition I read, skills and understanding. That's an immense task. It's not one of the TAC's tasks at the moment and they say, "How do we do it?" But people are struggling with it and it needs to be done.

But this is a developed skill which we are all discovering and getting remarkable knowledge. We used to think that MRIs were marvellous but now it's FMRIs, if you've got the money for it. I can count on one hand how many there are in Melbourne. You can actually see what's happening as you work with the brain and with the person. This is all happening around us but we're not doing anything, really, about it. We've got this knowledge that we've got to absorb and we've got to apply it somehow.

MR KALISCH: Allen, can you point to countries where you think there are much better practices?

MR MARTIN (VBIRA): Where am I off to next week? I'm going off to Krakow in Poland.

MR KALISCH: In Poland?

MR MARTIN (VBIRA): No, I'm not suggesting Poland, because I haven't been there, but the international conference on rehabilitation of acquired brain injury is being held there. I would say - here we're in Victoria. Take a country like Austria. Smaller than Victoria. They've got an underlying philosophical position in their health system that every patient deserves the very best that medicine can offer. Now, that's a given in all their health systems. Diagnosed with an acquired brain injury in an acute hospital, the patient is stabilised, then is transferred to a hospital where every few months - and it's all disciplined - they have do a reassessment and rehabilitation can be started. The review after six months has got two options: stay or we'll go to another hospital. In this small country they have got five specialist hospitals who can take these people, introduce them to rehabilitation, develop their rehabilitation and progress them so that many can be returned to their families.

This is happening here with the occasional one. Some of the material which we are presenting in the conference next weekend - not this weekend, the one after - is of some special cases; one which was presented internationally two years ago, Now they've asked for a fuller one because then the patient was 11 years diagnosed totally incompetent. Then we can now report about - out of the nursing home, out of the isolation and a member of the community. Getting a letter from a parent, in this particular case, after seven and a half years saying, "Thank you for giving me back my husband; and my children, my three boys, a father." Now that, in medicine, drives us all remarkably strongly. But it has taken skill and the family was isolated. They hadn't got any access to this. It was only actually incidentally via an intervention by Rotary that there was movement which brought us into the picture. It didn't take long to realise what it was.

Now, I could go on with scores of examples of people who have been hypoxic and who have been neglected - well, not neglected but have been placed in nursing homes or even are held with families believing that that person is like this forever and through intervention at any stage of life that position can change. The best intervention is not immediately after the accident, probably, but after there's some settlement. TAC gives time frames which also sees them having a very different view about someone whose injury was seven, 10, 15 years ago and is being cared for by the family.

MR KALISCH: So your suggestion is that the evidence that you've seen suggests that it doesn't need to be early intervention in that sense, that it can actually be quite effective at a later stage in the right circumstances, the right care?

MR MARTIN (VBIRA): Well, yes. That's not ideal.

MR KALISCH: Yes.

MR MARTIN (VBIRA): Because we've lost those lives.

MR KALISCH: You've lost that opportunity, yes.

MR MARTIN (VBIRA): But what you then have is an adult who has no memory, has to be trained how to eat, has to be trained by the carers and the ones which the services providers can provide to look after the basic activities of life, learn a language, understand - and has to be treated by those who do it who have that understanding as well.

MR WORSNOP (VCASP): I should just add, sorry, one of the issues I think that's clear is that with recovery from ABI interventions need to occur to capitalise both on passage of time and also when interventions can be most effectively worked on. One of the problems with our current system, even with the good systems like the ABI Slow to Recover program, is that there seems to be a driver to diagnose, assess and deliver very quickly. We need a system that actually can be responsive so that if people aren't getting services immediately, because it's not seen as necessarily appropriate, they're not in a state of fear that they will never get them ever again. That's one of the core challenges to try and build into a new system, that way. Sometimes it's community services systems that actually are holding people for a long time, until sort of a therapeutic intervention can be most effective.

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

MR WALSH: I was interested in your comment comparing the TAC and the public systems, that there are pros and cons. How would you design a system that had the best of both worlds? What specific things would you be looking for?

MR WORSNOP (VCASP) : Yes, that's a $6 million question, isn't it?

MR MARTIN (VBIRA): It comes in two parts. Firstly, the people concerned should be skilled in rehabilitation. If that can be overcome, the service providers have a different situation than where there's ignorance.

MR WORSNOP (VCASP): Clearly one of the benefits of the TAC system has been with the no fault insurance concept, where basically people are getting access to services as quickly as they can. There's not an issue of trying to figure out whether there's a liability or not. That's significant, in terms of being able to get access. The problem with it though is that the driver is often fairly medicalised. There's a demand to try and actually get people's prognosis sorted out very quickly so that the pattern of services can be actually established really early.

In the public system the problem is the rationalisation; so you don't get access, because you go on to waiting lists. If we could actually get a system where you are more able to be responsive, in an early intervention sense, but not have this driver of having it to be so much based on prognostic and diagnostic types of assessments so early and not be able to then reconnect with people over the long haul. I think the combination of those two somewhere is actually what we need to aim for.

MR KALISCH: To what extent does your understanding of a good system also engage with families, in terms of providing them with information, awareness, skills, capabilities?

MR WORSNOP (VCASP): I think it's a completely untapped resource most of the time. This is assuming there is a family on board, mind you; we are talking about adults sometimes who either don't have or don't want their family involved. But where there are families involved, they often cry out for, "I want to be able to do something useful." The system is directing people towards therapeutic interventions and all that sort of stuff, but there's not enough capacity within that to support families to learn some of techniques and supports that are required to assist in the rehabilitation process.

MR MARTIN (VBIRA): Families are the best observers. They will discern and tell you, if you are in a good relationship with them, that, "He moved a little finger," or that, "Those eyes are starting to move and follow something," because they're beside the bed so many hours a day, etcetera, if the therapist and the carers can interact with that family about that individual patient. No two ABIs are the same, you can't put them in boxes; you might have a diagnostic label for some, but that's only as to cause.

MR WALSH: Just a little bit about I guess the less physically-affected people with brain injury who have, to an untrained observer, no disability but they have cognitive and behavioural problems. We have heard a lot about direct funding and direct payment and direct employment of support workers and so on. I'd like to know a little bit about how you worked with people with that level of brain injury in managing their support needs.

MR WORSNOP (VCASP): This is actually really quite a difficult area. Underlying the whole philosophy of individualised approaches and stuff, you need to base everything on that approach. The difficulty I experience within our system of support for people with ABI is that there are a lot of people who have significant cognitive deficits that mean that their ability to plan, their ability to manage funding, are actually really quite compromised, and putting them in a position where they actually have to do that often results - and we have seen these results already in Victoria - in services not being delivered, because there isn't actually a way in which those people are adequately supported to do it.

Ultimately there are capacities to support just about anybody. I know of a particular case of a young man whose capacity to communicate his actual wishes is fairly limited but the family and the friends around him have a system where they actually virtually triangulate their expectations with their experience of him before his injury, and they are able to actually collectively put together a plan which would actually address his needs. It's very resource intensive, but adequate; because in the end run you know that the person is actually getting their dreams and their desires met. But I do think that there is a need for a system which actually does support people before they're actually at the point where they can actually take on those roles.

The danger I have seen already in the implementation of individualised approaches in Victoria is that there is an emphasis to try and actually push people into that capacity perhaps too soon, in some cases, and perhaps it overlooks some of the key problems. Like, ABI is often associated with trauma, and there is a lot of post-traumatic experience going on that affects people's ability to make good decisions. Similarly, there are significant cognitive deficits, like planning and insight, that actually do affect people's capacity to really manage a system themselves, and I think there are expectations that sometimes can overlay the goodwill and the good idea of actually individualised funding driving everything. However, I think we always need to keep in mind that that's what we're aiming for in all instances, no matter how injured a person might be.

MR MARTIN (VBIRA): "Expectation" is a good term that we get thrown back at us so often, because "he used to be" or "she used to be". It's a new life now, a different life. So the WorkCover formula for a chartered accountant who ran a business, "Get him back into work, and happy," as far as the employer is concerned or WorkCover is concerned, if that person is employed, "five days a week," but where and what level? That person's memory is possibly coming back and the development is there, and being the check-out person at a service station is not what he wants. Through the intelligent work of service providers, creating that new life that satisfies that person is the challenge that we all have. But the reality of some systems which say, "Oh, he's back at work, so that's it" - that's monstrous.

MS SCOTT: John, are we just about wrapped up with the questions?

MR WALSH: Yes, thank you. Thanks, Tom. Thanks, Allen.

MS SCOTT: Tom and Allen, I might leave you with a bit of a wish list. You have made a couple of remarks and gone into topics we haven't covered before and we haven't seen in our submissions yet. I appreciate that you're going to make a submission, but I guess the commentary about how far behind you thought services in Australia or techniques in Australia were relative to overseas, it would be good if we could get some evidence on that; some analysis of TAC's strengths and weaknesses versus the public health system would be very much appreciated.

You talked about multicultural settings. We have had other people give us evidence on multicultural settings, but clearly that's an important dimension that we'd welcome your input on. I guess skill sets and individualised funding models, their strengths and weaknesses, when it's appropriate, when it's not appropriate, how we could give advice to the government on when it is appropriate, we would welcome that as well. By all means, cover other topics if you wish, but I think the fact that you've touched on those today and we haven't necessarily heard your insights from anyone else, we'd welcome your material on that. Thank you very much.

MR WORSNOP (VCASP): Thanks for giving us a few more months to do it.

MR MARTIN (VBIRA): I could give you some reading material, if you like. The British government has a practice that every year there's a multi-party issue on health, and in the year 2000 they set acquired brain injury, and the committee travelled all over Britain, it took 12 months. In 2001 I happened to be in London when it was presented to the parliament, and the opening phrases from the chairman was that, "If this parliament doesn't do something, this is going to wreck the national health scheme," and that's a very scary thing for Britain. That's a lovely, thick volume, if you'd like to read it.

MR KALISCH: If we can get a reference, that would be useful. I'm sure some of the staff at the commission will be reading it.

MR MARTIN (VBIRA): The skill training doesn't stop with just the carers, and we are carers at any level and we are learning. What's VBIRA? It's a collection of therapists and medical people who are all involved, learning from each other, learning about the research. We have no staff, but you can come along in the September for an all-day workshop, 200, because that's the capacity of our auditorium. They will be hearing and they will be interchanging, because there are people in all these walks of life, professionally, who are involved with the service providers and with patients, because we're all learning.

MS SCOTT: Thank you, Allen. Thanks, Tom. We're going to have a very short, five-minute break, because we have people who are going to be presenting this afternoon and we need to stick to a time frame. So back in here in five minutes, please. Thank you.

MS SCOTT: Good afternoon. We might resume our hearings now and welcome to the table, Michael. Michael, I think you're representing yourself rather than an organisation.

MR MERRETT: That's correct.

MS SCOTT: Michael, I might just get you to say your name into the microphone, and then if you'd like to make an opening statement, feel free to do so. Or, if you'd like, we can just go into asking you some questions. But you might just want to say just a few opening words, if you like.

MR MERRETT: My name is Michael Merrett. I'm representing myself. I live in Richmond and I'm just here to talk on a few different things that I'm working on. I agree with the National Disability Insurance Scheme, I think that's a great idea. That's my opening statement. Thank you.

MS SCOTT: Okay. David?

MR KALISCH: Yes. I just noticed that you have also worked for the Australians for Disability and Diversity Employment. I'm just wondering whether there was anything from that experience that would be of benefit to us in thoughts about how we could design the National Disability Insurance Scheme.

MR MERRETT: I think anything that helps people with disabilities get into a gainful employment situation is a good thing. I've struggled to find employment my whole adult life, and it's only through the disability employment network WISE Employment where I got a chance. I saw that the federal government was putting in $4 billion from 2006 to 2010 to help people like me get into employment and I thought "Well, I'll give it a go. I should be able to get some of that $4 billion somehow. I'm in with a fair chance."

I was born with a permanent disability. My whole life I just didn't have any assistance from the government to provide any support for anything really, apart from the Disability Support Pension, which I got on straightaway as soon as I could. I think I was about 17 or 18. It was 1987, so I would have been 16, I suppose. I have had four part-time jobs with Australians for Disability and Diversity Employment, an implementation project worker for the launch of a survey they did called Leading from the Front, where they surveyed 45 different non-profit organisations and found out how many people are employed with disabilities.

It was a very low percentage, and so they had eight key findings and strategies to improve that employment rate. So that was at the Human Rights and Equal Opportunity Commission. That was a three-month job, in 2008. Recently I have had two go's at being the membership development officer; that has been good, but that concluded recently because they ran out of money. So if anybody has got any funds for that job, that would be great. There's probably a conflict of interest there; sorry about that.

MR KALISCH: Do you want to talk about some of the learnings or experiences, in terms of some of the constraints for people with disabilities getting into employment? Is there enough money for workplace modifications?

MR MERRETT: Yes, workplace modifications are very good. I got a $1500 office choice - so I was quite keen on that - which was very ergonomic and made sitting at the desk very comfortable, because I have got a bad back, scoliosis - you know, not to give too much information, but there are rods and things like that, so it can be quite painful to sit for a long period of time in an awkward chair. The only thing, they wouldn't fund a computer, they said that was up to the employer and that it was a bit too difficult and costly to manage. It was a reasonably good computer and it did the job, so I'd have to say it was quite good.

However, when I was starting out to get employment I was on the pension and I'd go along to WISE Employment, for about a year I was going there and they helped me with my resume and things like that. I thought that was quite good. I had to go out and buy clothes and I had to get - for my state of mind and the way I wanted to operate, I wanted a mobile phone. For years I've been upgrading my computer, since 1993. Every chance I'd get, I'd get a faster computer. So now I've got quite a good computer, top of the range. Well, not top but funded through - a no interest loan - the Good Shepherd. The latest loan is actually a step-up loan through the National Australia Bank and the Good Shepherd. I actually met the group CEO, Cameron Kline.

MS SCOTT: Yes.

MR MERRETT: Do you know him? What's his name?

MS SCOTT: It's a Scottish name like McIntosh or something like that.

MR MERRETT: Yes, something like that. He was quite nice. That day he was handing over $15 million to the Good Shepherd and that was good. They invited me to the no interest loan forum a couple of years ago, so I spoke, to give my perspective on their loans. I've tried to increase my own skills to be competitive in the employment market and it's worked quite well so far.

MR KALISCH: The other aspect you talked about in the document you gave to us before the hearings was around accessibility and transport access in particular.

MR MERRETT: Yes, my favourite subject.

MR KALISCH: I'm wondering are taxis too expensive and not enough support for taxis to provide - - -

MR MERRETT: Personally I don't particularly like taking taxis. For one, they cost a lot of money to take a cost, and from all the stories I hear they're very hard to get booked on time to where you want to go. If they were free and if they were on time I'd probably take them. They're not, so I take public transport. To get to work I get on a Jolimont train station which I had to scooter up Bridge Road to get to there, and all the tram stops along Bridge Road are inaccessible, so I've been campaigning to get accessible tram stops put along Bridge Road because I can, you know. It's not because I want them really, I can scooter to Jolimont, and I've been scootering into the city, back and forward for 20 years.

MR KALISCH: Is that how you got here today?

MR MERRETT: Yes, it was. I'm only five minutes from home, actually. It's very handy, a nice coincidence. It's kind of like a sign, if you like, that I'm here and talking about all this. If you're in Richmond, the best suburb in Melbourne, as I always say, it will be even better when we've got accessible public transport. I've been campaigning hard for that, and I found out a couple of weeks ago that at a Department of Transport forum - they officially said in public - that they're going to go ahead with the Epworth Hospital development accessible tram stop, because they don't have an accessible tram stop in front of the hospital, which is not very good.

There's the other project which I've been campaigning which is the free public transport for 26,000 - I almost blush when I say it actually but it sounds pretty good. But 26,000 scooter users in Victoria with permanent severe disabilities will hopefully by the end of the month get free public transport on buses, trams and trains and V/Line in Victoria indefinitely based on the fact that the whole Victorian public transport network is independently inaccessible. Lynne Kosky did that, she agreed. That was one good thing she did before she left - that I know of anyway. She probably did many others, I don't know. It's not just my group, there's a whole group of us and we all work together and as individuals and we put it to the Department of Transport that it wasn't fair that we couldn't access public transport so why should we pay for it.

Incidentally for 10 years or more unofficially it has always been free for people with wheelchairs and scooters. But that's just me saying that. That's pretty good, and we're going to get Myki swipe cards for a scooter wheelchair access pass and we won't have to put any money on it. I'm pretty pleased about all that, although I don't believe it until I see it. I haven't seen it yet. It was supposed to be out in March, but they have along the way told us why it hasn't been available yet and that it will be available by the end of the month. Again, in the public forum the other week, they did say that it was coming, so that was good. It's been difficult working on all these projects as a volunteer but if you've got the real experience I find no matter what you're trying to advocate for - be an actress or whatever you like - it seems to be the only way you can get anything done is to have a small group of individuals who believe in something or have a small group that's not funded by the government or funded by an organisation.

Then if they're in the right and they're on the right track and it seems like a fair thing, then I think you can make it change, even small changes in there. If everybody had the same idea it would change the world maybe. It's a bit idealistic maybe, but I've had a pretty good time of it in the last year; worked on little projects. I'm hoping maybe other people do similar things, you know.

MR KALISCH: So if the government was to think about the design of a new disability support scheme, what would be one or two of the main things you think they should concentrate on?

MR MERRETT: Well, there's what I've struggled with, as I mentioned. It's been hard to get equipment to improve my own skills. So clothing and basics for being employed, it would be great to have a $5000 start-up grant. You could work with a case manager or something, "Look, we've got five grand here. What do you need? Do you need a computer? You need some computers. You need this, that and the other. All right. Here we go, here's a plan. Let's set some goals and get you into employment and you'll be all set." That would be great, $5000, you know. The disability employment networks have hundreds of people on their books. There's about 400 agencies or something all around Australia. They get money, thousands of dollars for every person they have on their books. If the person gets employed they get more money off the government. Where has this $4 billion gone really, seriously. It's crazy, but that's just my opinion. I would like to know where all the money has gone.

I know there's a lot of people in these disability employment networks are employed, and they don't seem to have disabilities. Maybe one or two do out of 20, and they have a real high turnover rate. I'm just talking about WISE employment. Mind you, they have helped me out a lot so I can't complain too much but it does make me wonder. Everybody knows that the federal government has wasted billions of dollars recently on other things, so it wouldn't surprise me if they have wasted a lot of money in the disability sector as well. But that's just me being a bit sceptical. Sorry about that.

MR WALSH: Michael, can I just ask a question, it's John in Sydney.

MR MERRETT: Yes, sure.

MR WALSH: I'd like to know - I mean, we talk a lot about employment for people with disability. You said you've had some good experiences over the last few years in employment. I'd like you tell us, I guess, what you see as the benefits of being in employment for you, how it makes a difference to your life?

MR MERRETT: Sure. Being employed, I've probably averaged out maybe six months of the year employed. When I am employed for eight hours a week - I was employed for 10 hours there at one point, but it's really good to go to work and work in the workplace and be included with people without disabilities, to learn new skills and to get into a routine. It's much better than sitting home, watching TV. Mind you, I did that for years and years but I'm not so much lately, now that I've got all these campaigns that I'm working on. I'd say it's very, very good just for motivation and confidence.

Last year I did a leadership course at Leadership Plus through Action for Community Living which Australians for Disability and Diversity is a project of Action for Community Living as well, and that was created by Peter Rickards who was in Leadership Plus and graduated in 2005. So there's a lot of good things coming out of there. It's get up in the morning, go out and catch a train and go to work. It's a bit unusual for me really, you know, thinking about it in my whole life. I'd say it's very good.

MR WALSH: Thank you.

MS SCOTT: You said earlier that you hadn't received government support except for the DSP - Disability Support Pension. Under a national insurance scheme is there support that you think you should be eligible for or would like to be eligible for? You think you've got the support you require and you're just going to keep powering on and see how you get on with employment?

MR MERRETT: Yes. Personally, I'm a very independent sort of a person. For years I did have, believe it or not, Meals on Wheels delivered to my door. I went through a bit of depression and all this, and I was probably a bit lazy and not very organised and all this sort of thing in my 20s. I had home help with one hour a week they would come around and vacuum the floors and all that sort of thing. But after a while I got a bit sick of being locked into being there. I wanted to be out and about and doing a few things, so I just in the end stopped it. It was costing me money too, money that I needed to live. It wasn't much but it was enough when it added up. Like to have the Internet and a mobile phone and a house phone, that's a big bill right there. I pay about $90 a fortnight just to keep my computer and the phones running.

One of my main problems with employment - and I've got a copy of a petition here. This is to do with my Centrelink group on Facebook and it's called Stop Centrelink Income and Assets Testing the Disability Support Pension. I've got 101 signatures here, I believe. It's directly to Kevin Rudd and the House of Representatives which I'll send a copy of it to him. I figured since this Productivity Commission inquiry is funded by Kevin Rudd that this might be one way of getting to him hopefully.

MS SCOTT: Well, it's interesting that you've mentioned this issue of means testing because we've had other people today talk about the fact that they don't think the eligibility for the scheme and whatever the scheme provides should be means tested. It is one of our questions in our issues paper. So in that way it's directly relevant.

MR MERRETT: I had a look at one of the other submissions on the web site of the Productivity Commission. I'm not sure what that guy's name was. It might have been Richard - anyway he's got a consulting group that consults with the federal government or something. He had a very detailed paper he submitted which outlined a lot of the income and assets testing of the disability support pension and what it would cost and what it does cost. From what I could work out it was only about 300 million tops. It might have been 260 or 290 million if the income and assets testing was taken off the disability support pension. That's out of $11 billion or whatever it is. It's only like 250, 260 million. What a difference that would make, an incentive for people to get into employment. It's just crazy. Where's the incentive to go to work when you can earn $142 a fortnight. You're only working eight hours a week, so you're only getting $327 or something a fortnight.

They take 50 cents out of the dollar after $142 and then you ring the Minister for Housing, Department of Planning, and they take 25 cents out of the dollar, 25 per cent of your income. So 75 cents out of the dollar is a pretty high tax rate when you think about it. Who pays 75 per cent tax on money you earn? Maybe I'm getting confused with my mathematics there and tax rates. However, it's rather high and rather a disincentive. Wouldn't it be more productive - the Productivity Commission - to have people in employment - excuse the pun. Yes, it would be much better to have people wanting to go to work. I mean, people do want to go to work but it would be better to give them more incentive. That way they can have more choice about paying for a mobile phone or a computer, rather than have to rely on hand-outs. Isn't that what you're talking about here, to give people more choice?

MS SCOTT: Yes, it is one of the issues. Michael, your scooter, did you have to provide that yourself? Did you have to fund your scooter yourself?

MR MERRETT: No, not at all, because I've got a permanent severe disability, muscular dystrophy - well, it's a rare form of it, and with me it doesn't deteriorate, so I'm lucky - the government pays for the scooters which is very handy. I appreciate it very much. However, I've got a big problem with the scooters because this company that built this was an Australian company. They designed the Dick Smith solar car that went across the desert. They're in Sydney but their company is not making these scooters any more, because I entered in my opinion it's $5600, and the state and federal government have put a ceiling of $4000 on scooters. They had to buy this one from some shop up in New South Wales and I had to find the extra $1600 to fund it. They shipped it down. They're not making them any more so I've got to look after this one now.

MR WALSH: Michael, did you have to wait long to get the scooter?

MR MERRETT: I had to wait a year and I had to fight tooth and nail to get it. It was not easy. As you can imagine, it's not easy for me. Imagine all the other people that can't speak for themselves properly. They're just being given rubbish basically. I call them ice-cream containers on wheels. They won't last. They're no good for getting over bluestones, cobblestones in Melbourne conditions, in my opinion. While the public transport system is inaccessible for wheelchairs and scooters with the little wheels - and they've all got them - there's a discrepancy here, a big one, and it's not making people with disabilities socially included in the wider community - in public transport accessing, employment. Employment and public transport are my two big areas.

MS SCOTT: Michael, thank you very much. Thank you for coming along, and thanks for your piece of paper that we got earlier. John, I've finished with my questions. David, are you finished too?

MR KALISCH: Thank you.

MR WALSH: Thanks, Patricia.

MS SCOTT: Thanks, Michael.

MR MERRETT: I hope it helps.

MS SCOTT: I know someone wanted to make a comment but could we hold off to the end because we've just got a few other people to go. Is that all right? Okay.

MS SCOTT: All right. Well, I think we're keeping to our schedule as tightly as we can. So welcome to Lorina. Lorina, if you could identify yourself for the transcript. I think you're representing yourself. Is that right?

MS NERVENGA: And my family.

MS SCOTT: Your family?

MS NERVENGA: Yes.

MS SCOTT: Yes, all right, good.

MS NERVENGA: So yes, my name is Lorina Nervenga, I'm a resident in the state of Victoria. I am here representing my family and our experience, which I'll just read to a statement that pretty much explains it all. So the focus of my presentation will be firstly on how the current system addresses the needs of the children of traumatic brain injury or TBI sufferers. I offer this in context of how improvements to the current scheme could be made to better assist other families, particularly the children or dependents of TBI sufferers. The second part of my presentation will look at access for people with disabilities in public buildings, specifically state-owned assets such as public hospitals and public facilities. I do want to make the distinction about public-owned and state - you know we own these assets, as opposed to public buildings which is your shopping centres and your retail outlets and commercial buildings. I'm specifically talking about buildings that we own as a community.

These points draw from my own personal experience firstly where my partner suffered physical and psychological injuries, including a traumatic brain injury, from a motor vehicle accident in 2006. Secondly, before, during and after the accident I was also sharing the part-time care of my elderly mother with my siblings who was at the time a diabetic, visually-impaired cancer patient. My mother passed away in 2007. I offer this in context of me also being a registered architect in the state of Victoria, knowledgeable of the regulatory framework as well as the building regulations on disability access and also recent changes. I should also declare that I am currently director of building policy at the state government department of Planning and Community Development, although at the moment on a secondment in another part of government. So it is an area - I have reasonable knowledge.

MS SCOTT: Yes, fair enough, thank you.

MS NERVENGA: I have three recommendations which will be given below. So the key points from the issues paper that my submission will address will be which groups are most in need of additional support and help - and I'm not sure about most but certainly I have some suggestions there, and that's recommendations 1 and 2; and what kinds of services particularly need to be increased or created. Again, this is just my view based on our experience.

So firstly, on TBI, or traumatic brain injuries, and families. Since the accident in 2006 I've been primarily responsible for the overnight care of our two children seven nights a week while also being employed full-time. My partner, who is also my ex-husband and I - well, we have two children currently aged 14 and 16 who at the time of the accident were aged 10 and 12. Prior to the accident the children were in my care four nights a week and with their father three nights a week. We'd only been divorced for a matter of months, so it was a very new arrangement. The accident precipitated us reuniting. So although we do not live together we did reunite as a couple immediately after the accident. Over the last four years my partner has increasingly been able to increase and share in their practical care and since receiving a TAC settlement mid-2009 also provide ongoing financial assistance. He is now on a permanent disability pension.

The accident has changed the way we function and interact with each other as a family but significantly for the children, as it occurred on the onset of puberty for both of them, adding more complexity and challenges. The impacts of the physical injuries were obvious and easy to grasp, albeit hard to witness, particularly for the children. Their once vibrant, physically fit father was afflicted with much pain that persists to this day. It is only his tenacity and commitments to physical fitness and the nature of his injuries that has allowed him to make a remarkable physical recovery. The TBI has been a much invisible and incomprehensible affliction and there has been a continual process of gradual conditioning and awareness over months and years that we, as his family, have had to come to terms with. The ongoing nature of the recovery and at times no progress has been difficult for me to grasp as an adult. For the children I can only offer that their experience must have been one of ongoing grief and incomprehension.

I would like to read part of their affidavits for their father's case. Our daughter then 14 wrote:

> Before his accident my dad was a happy man who joked around a lot and had an incredible mind. He used to be able to design and construct robotics in his head and had a near-photographic memory. Now, after the accident, his personality has drastically changed. He cannot multi-task, he cannot concentrate on one thing for long periods of time. He becomes nervous and cannot cope in crowded areas. At night he cannot even dream any more. It saddens me deeply to see my once happy father turn into a serious, controlling man.

Our son, then aged 12, wrote:

> Before my dad had the motorcycle accident he was much more enthusiastic about what he did in his life and he was much calmer and less worried about the things he loved to do. This affected me in a way

> that I can't talk to him like I used to without him giving me safety lectures in every conversation. When I found out that my mum and dad still loved each other and wanted to get back together and that dad was probably going to move back into our home, it made me feel very happy but he didn't end up moving back in because he was worried about us being scared of him, and that's because of the accident. I feel sad that dad is the way he is now and that he is not going to move back in.

That's their statements. These last four years could have transitioned in a more positive way for our children had we had more access to information or counselling, particularly in terms of the unknowns and what to expect. As it was, things unfolded in a complex manner. We were all in the dark about what to expect and how to cope, in many instances. I observed my children at times frustrated and sad at their loss and what to make of how things were. In our experience the children of TBI sufferers are excluded from any specific guidance as to what is going on and what can be expected. Our experience was one of having to see how things evolved and manage on a daily basis the different stages of recovery which included ongoing confusion and trauma for the children.

So my first recommendation is that people who suffer TBIs and their families should be given more information on what to expect and how to cope in the early months of recovery and for the longer term of rehabilitation, including specific guidance and counselling for the children of TBI sufferers. My second recommendation is that drawing from examples of overseas support information - we should draw from these examples, as in my experience the most useful information was obtained from a US web site just through Google searching three years after the accident. The type of information accessed was clear on what to expect and how to cope with the changes in the TBI patient. It would have been very helpful to have been able to access this type of information earlier so I could have been able to explain more to our children.

So my second area was really to talk about access for people with disabilities in public-owned buildings. Again, I would like to stress these are buildings that we own as a community. They are not owned by the government, they are owned by the people. In 2005 it was my role to take my mother to her chemotherapy sessions at St Vincent's Hospital in East Melbourne. The care given to my mother was exemplary and I am deeply grateful to the many that assisted in her care in our public system. As an architect I was aware that the public buildings we frequented together met with minimum building regulatory standards in terms of disability access. There is, however, a role governments should play in the procurement of public assets, and meeting minimum standards is a low benchmark to meet.

There are many examples of access points in our private hospitals where better innovation and design could lead to a better patient experience, particularly where the patient has a disability or illness. State-owned assets should aim for best practice, not merely meeting minimum standards. The same flight of stairs which is the shortest access point to the chemotherapy ward from the main street entrance was still there 25 years after we had taken my father for his treatment and subsequent passing. The longer and more circuitous route that did not include stairs was always harder to achieve with a sick, elderly patient in tow. I believe that simple criteria for achieving best practice built assets in our publicly-funded buildings should be a given. There is much data to support that high quality buildings in health care lead to better recovery rates and patient experience and there are overseas organisations such as the Maggie's Centres in the UK and the Pebble Project in the USA that support this.

So my third recommendation is that government or publicly-funded buildings as a priority should aim for best practice examples of disability access and to high quality design in new and refurbished health care buildings in all future public construction procurement policies. Thank you.

MS SCOTT: Can I just ask about your last recommendation. I know at the Commonwealth level that the Commonwealth stipulates energy ratings that need to be achieved. I have to say I don't know what they stipulate for disability access. I'm sure it's probably the minimum requirements. What operates in Victoria? What's the current standard that people have to aim for?

MS NERVENGA: The state requirement is to meet with the National Building Code of Australia. So it's really the Building Code of Australia that sets the standard. State by state across the country there are different areas where, for example, in domestic construction there are different regimes operating where one in five new residences in a development might need to meet disability requirements. But it's not full disability access as we understand it. It's just visitable access for people with limited mobility. So we start to get into the terminology there.

The point I'm trying to make here is that standards can only really be set for minimum compliance. In terms of government as the largest client of the building and construction industry they can play a pivotal role in affecting change and really showing just what can be done. We have brilliant architects and procurers in government as well as in industry that are able to produce high quality buildings. But the procurement policies really need to align with that aspiration of producing the best possible dignified access for all.

MR KALISCH: Is there a sense in which some of those access regimes can be improved at minimal or moderate cost or is it a high cost dimension to change the standards?

MS NERVENGA: No, well, in my experience - and as I said, I am director of building policy, we are working on introducing some visitable standards; standards for people in the residential sector. So the costings we did supported that the best opportunity to, I guess, implement some better access is at the design stage, the design and innovation stage.

MR KALISCH: Yes.

MS NERVENGA: That, I guess, is really - it really points to the fact that if you don't do it at the beginning and it's not in policy then it's not going to necessarily occur. You can't sort of just wait for it to happen by attrition. There has to be, I guess, a real commitment.

MR KALISCH: Yes, thank you.

MR WALSH: Lorina, you mentioned that you can only set standards for minimum. How would it be possible to specify best practice for government buildings?

MS NERVENGA: Just in government's own policy-making, and governments across Australia agree to procurement policies at the Australian Procurement and Construction Council. Victoria is represented by the Department of Community Development as well as the Department of Treasury and Finance at that forum. It's a ministerial council and it actually has a lot of weight. Decisions are made and agreed to, if you like, at that forum. So if there was a coordinated commitment across Australia to raise standards in public construction procurement at that forum I think there could be a lot of good that could come out of that. Also, look, it is very important to see what they're doing overseas. There really has been commitment in this area all over the European Union and there's some extraordinary projects happening in the US as well. There's an enormous amount of data to support that high quality design does lead to better recovery rates and patient experience.

MS SCOTT: Would you be able to include that information about evidence on improving recovery and so on in your submission or just make reference to it?

MS NERVENGA: I did make reference to it earlier, so if it's in the transcript - it's the Pebble Project in the United States and it's the - - -

MS SCOTT: Okay. So it's that one. Sorry, you did mention - - -

MS NERVENGA: Yes, the Maggie's Centres in the UK.

MS SCOTT: Yes, thank you.

MS NERVENGA: But there are numerous around Scandinavia and northern European jurisdictions where they really have put a lot of effort into this area.

MS SCOTT: Okay, that's good. Thank you.

MS NERVENGA: Yes.

MR KALISCH: So your husband, as I understand it, was a TAC client. I'm just sort of thinking about sort of how that actually operated in practice, particularly in terms of engaging with the family. You seem to be suggesting that things could be improved and I'm sort of wondering - - -

MS NERVENGA: Look, just on that, I'll have to say that I was fortunate that I was in full-time employment. It was a bit of a double-edged sword though because it meant that I had to hold a senior job while my children were in need of full-time - you know, in need of care. So the system didn't recognise me as his partner any more. All the discussions around his settlement were really around him as an individual. I don't believe the children, as his part-time dependents, were really factored into the settlement. So it's just unfortunate that the children were very much excluded from a lot of the thinking in the scheme, whether it was in the payments but, you know, just even in trying to support them - I mean I had trouble understanding really what was going on and I consider myself able to grasp complex information. But we just didn't know what to expect and what was going on. We were given very little information. It was quite a load.

MR KALISCH: Do you have any sense as to whether that would have been different if you had been together at that stage, whether there was family support services generally provided by TAC or others or whether it's just an aspect that could be improved?

MS NERVENGA: The point I was really trying to focus on was that if I had had more access in terms of what to expect with the recovery stages or not, you know, I could have explained that to the children. But we were kind of just fumbling in the dark. There was just this constant sense of trying to pull everything together and to keep a job going. It was - and my mother passed away. So I mean from my own point of view it has been a very difficult time. But the children, I believe, just - you know, I could have explained to them, "Well look, you know, it's going to take six months before we see anything or it can take up to three years to see this," but we just weren't given anything. It was fortunate that he was able to leave the hospital walking but it was almost as though he looked - we thought he must have looked too well or something because there was no follow-up, for me at least. There was no counselling. I think some counselling for the children could have really helped; social work, something, for the children.

MR KALISCH: Yes.

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

MR WALSH: Yes, it's a difficult one. I mean I don't quite know how to ask this question because there's a point when I think at the immediate injury it's really the acute care system, the public hospital system, that's most involved. Then at some point the responsibility is handed over to the insurer or in this case the TAC. It almost sounds like that handover and the involvement of you in that handover wasn't managed maybe as well as it could. Is that your recollection of how it happened?

MS NERVENGA: Partially. Look, I only had one discussion with a social worker the day after the accident and quite clearly this woman knew a hell of a lot about what was going to ensue. She was enormously supportive and I drew a lot of strength but also an incredible outpouring with this stranger in a really short session the day after the accident. That was it. I never had another session with anyone really again. I really believe that, you know, if the children had been sat down a week after the accident or even a month by a professional with me or both of us present we could have perhaps just at least explained something. But we just fumbled along and just - nothing really ever happened. Three years later I was still trying to understand it. It was frustrating for everybody, particularly for the sufferer, for my husband, my partner, because he didn't think anyone really cared. It's just really difficult to explain; we all cared deeply, but we just didn't know what had happened. The key point really was on guidance and counselling for children of sufferers. Lives change, and there's people out there that have got a lot of knowledge and information, it would just be great to make that link to perhaps the most vulnerable. I really saw the children as the silent victims in the whole episode.

MR WALSH: I think, in general and for yourself, you must have needed a bit more support than you were given, it sounds like.

MS NERVENGA: Yes and it did catch up with me late last year. It was two years after mum died and four years after the accident. I felt like I had been running a marathon for four years. We are lucky, it could have been a lot worse. I am very, very grateful for that. But it has also been very challenging.

MS SCOTT: Thank you very much. That's very good.

MR KALISCH: Thank you very much, Lorina.

MS SCOTT: Just before we start with the next witness, is there anyone who would like to avail themselves of an opportunity to make a brief comment at the end of today's session? Is there anyone who wasn't formally on our record that does want to say something on the record at the end. No? Okay. Thank you. We welcome to the table Les and Adam. Over to you. You might just identify yourself for the transcript.

MR COPE: Thank you very much. I'm Leslie Cope and my son here is Adam Cope. We are very pleased to come along and be part of this presentation and we thank you for the opportunity. Do you wish me to begin?

MS SCOTT: Yes, please.

MR COPE: I did supply some notes. I don't intend to actually read them, but I understand you do have copies of them. I'll just talk to them, if that' fine.

MS SCOTT: That's fine.

MR COPE: If you have any questions, please don't hesitate to stop me.

MS SCOTT: Okay.

MR COPE: Adam has had a very interesting journey over the last 37 years, a journey I believe that's quite different, quite unique, on the shape of things, from where a lot of families have come. We, as a family, have actually walked on both sides of the fence. We have actually been in segregated settings, we have been segregated from the community. We have effectively pushed that fence down. Over a number of years Adam went from what was a day training centre into a regular school.

He was initially categorised as severely and intellectually disabled. He moved into a regular school and achieved his VCE at year 12 level at the local secondary college. That was not an easy task. It was a very big journey, and one where we have done a lot of learning as a family. We come here as a family to actually share with you some of the good things; things that I believe could be taken on board by the commission in terms of supporting families and people with disabilities in their life's journey, because unless the families are actually supported as well the person with the disability in the family, his or her aims and goals and achievements won't be achievable as well as they could be.

Adam was put into the day training centre and within a matter of months or so he was actually on the list and the Department of Social Services, everyone knew who he was, he had a name, he had a number and so on and he was in the system. The interesting thing is that when he actually left the school he had apparently disappeared off the list. It's almost as if, "You've gone to school, so you must be okay and you must be fixed." So it took us probably another 10 years or so after leaving the school to actually get him onto the list. The list is that list that actually determines, "When support comes up for an individual, we'll be able to provide you with that support." So we did get him back on the list in due time.

We have worked with a number of agencies who have supported us over the years with Adam, in terms of support people. Some of them are very efficient, some of them not so efficient. We eventually actually started up our own management group for Adam. We have an organisation called Ability Dignity and Access Management, which is ADAM Inc, and with that we actually receive funding from DHS Victoria and we employ our support people for Adam. Adam has support from about 9 o'clock in the morning till about 5.00 each day, seven days a week, and after 5 o'clock we, as a family, then take over.

It's not all that easy, because in fact some of the support comes from several agencies and one of our major things has actually been getting all of this funding into the body. There's an enormous administrative cost when we're getting funds from about three other different agencies and they're coming to us. So they have their administration costs which they take out before the money comes to us. We get the money and we obviously have administration costs that we have to incur, because we obviously have to pay someone to manage the funds and so on.

MS SCOTT: Are you comfortable if I ask questions as we go?

MR COPE: Of course, yes.

MS SCOTT: You said there was money coming from three other agencies. Can you just give us a sense of who they are?

MR COPE: All right. Do you want their actual names?

MS SCOTT: Yes, that's all right.

MR COPE: That's fine. I'll give you their names. One is Care Connect. The interesting thing is these three agencies all actually get their money from DHS in the first instance, and that's the crazy thing: Care Connect, Directions is another one, and Call Care. Actually there's another agency, there's also the local shire, the Shire of Yarra Ranges. So all of those agencies actually have funds and money that comes in a regular basis. Some of the money is paid directly from the agencies to the support people that we employ.

Some of the money comes directly to our organisation and we then pay the support people. But the crazy thing is that the money initially came from DHS, from the government, and we have raised this with them over the last four years and said, "Well, why can't you just move that money from those people and move it us?" They say, "It's not that easy to do that." I guess hey would be upset by losing their money. My belief is, "That's not our problem. You really need to organise that in some other way."

MS SCOTT: Les, do you get any money direct from DHS?

MR COPE: We do as well, yes.

MS SCOTT: So there's the four ways through various organisations, and then you get money direct as well?

MR COPE: That's right. Adam's funding from DHS is the Support and Choice program. I believe the name of that has actually changed in the last 12 months or so. That has probably been one of the most effective programs that we have been engaged in so far. It came across as a direct result of the 10-year plan that the Victorian government put together, which hinges on an individual planning process. So that's part of the thing.

The major thing I guess that I want to talk about today, further on down the track, is this planning process that I see as crucial to anything that this insurance scheme brings in, because I personally do not see an insurance scheme that just simply comes in with a pocketload of money and says, "Here's this family, here's $10,000," "here's $50,000," "here's $100,000, " that clearly is not the way to go. It needs to be targeted specifically at the individual and it needs to be based on a plan that actually is going to have some lifelong benefit to the individual, because, without that, we're just going to continue on down the same road that all the other states have done over the last 30 or 40 years in the scheme. So it's the individual planning that's crucial.

MR KALISCH: Can I ask just one quick question about the funding, in terms of what proportion of funding for Adam comes direct to you and what proportion would go through the other three or four service providers?

MR COPE: Look, these figures may not be correct.

MR KALISCH: Yes, roughly.

MR COPE: Roughly, I think there's about $60,000 that comes from DHS directly, and I'm only guessing, there's probably about $15,000 or $18,000 that would come from the other agencies. That seems like an awful lot of money, but all of that in total manages his support personnel for seven days a week along that process.

MR KALISCH: No, I was just wanting to get a sense of how much you directly have greater control over. So the majority is coming direct?

MR COPE: Well we do actually have control, in terms of the support personnel that we employ. All those other agencies are doing is they're actually paying them. So that in fact is a bonus.

MR KALISCH: Yes, quite.

MR COPE: I can always give you that, if you wish. Anything that I'm talking about today, if you want more information, please feel free to let me know and we can supply it. So here is Adam, at 37 years of age. He is still living at home with us and he is supported by us, and we're very happy to do that. But we're now both over 60, and so we're looking a little bit around the corner and just wondering what is going to happen in the next 10 years and so on.

One of the issues that comes up all the time with government bureaucracy is that someone, a bureaucrat - and I use that term, if you'll excuse me. In that sense, we're often told by bureaucrats that there is another family in greater need than us and they'll say that, "Mrs Smith is 87 and looking after her son and she has a greater need than us." Clearly that is quite true. But my question to the bureaucrat is, "Well, why is Mrs Smith at 87 still having to look after her son?" That really is a major part of the equation I think that we need to address, in terms of supporting people all the way down the track and not just waiting until the parents are literally at the end of their life, and then effectively doing something about it.

I just want to talk quickly about the grieving process. My best friend died 33 years ago and I grieve for him, I still miss him very, very much. But because he is no longer here and the event when he passed away was 33 years ago then my grieving for him has lessened. I'm committed now to the fact that he's not here, and I'm actually quite okay. With Adam, we go into the grieving process daily. Every time Adam is on a high we're quite elated and we're good, and then all of a sudden there'll be a minor thing coming in, or a major thing, and the grieving process will drop back again. So we're continually on this up and down spiral, and that certainly causes grief for us as a family, and I'm sure it does many other families as well.

Adam's mother had a minor stroke about two years ago, and that indicates an urgency there, and Adam needs to be settled before tragedy actually strikes. I'm firmly of the belief that the stroke probably occurred due to the stress and the pressure and the bits and pieces that we work through with Adam. Peta, my wife, Adam's mum, is a wonderful lady and she is the mainstay of the family. I'm there supporting her and I'm doing what I can, but she is the one who really takes a lot of the crunch when I'm not around.

I in fact had to leave my employment. I was a teacher and I took early retirement so I could actually be home working with Adam and giving my wife some time to herself as well. So it turns the whole family structure around. We're not complaining about that. I'm just simply explaining that it puts families under different stress levels with which the rest of society don't necessarily have to contend. Adam has in fact written a statement, which, if you don't mind, I'll read out to you. Is that okay, Adam? Yes. Adam actually takes a little while to communicate. So rather than actually sitting here and writing and spending the next 20 minutes while he puts pen to paper, he has written this in preparation for you:

> The reason I need support is to allow a wonderful mum time off. It's obvious that she is tired and stressed and worn out. If the support was structured it would make more sense. The old man is tired as well and he cannot cope on his own. When experts make decisions it's important that they have all the facts. The allowances that people make for me are always of a charitable nature. This is really poor and gets me down, rather than helping.
>
> If the committee puts its mind to it, the best outcome would be planning for individuals lives with the focus on the person; that way, all of society would benefit. "The teacher in the primary school said, when she had to support me, it made her look again at how she worked with other students. So it's not really rocket science. Just knowing about a person is enough to put a plan together that will be effective. The reason people with disabilities question the system is that they are always put aside as being too hard. This is painful.
>
> The state's 10-year plan gave me some hope, as it identified strategies and processes that could be used. Unfortunately, the bureaucrats did not apply its points as they should have. This has ended up as a plan for the system and not for the individual. If the commission reads the key points of the plan, a lot of work can be saved. I don't expect this document to have all the answers, but it's worth including as part of the big picture.

Here are some quotes from the 10-year plan: "Pursuing individual lifestyles to enable people with disability to pursue their own individual lifestyles by encouraging others to respect, promote and safeguard their rights and by strengthening the disability support system so that people's individual needs can be met. Individualised planning and support. The government believes that people's individual decision-making about their needs and the choices that they make about their lives should be the most important considerations when planning with and supporting people with a disability. This approach recognises the importance of earlier planning and support to achieve the best possible outcomes at all ages and stages of a person's life, as children, young people adults and as people with a disability age. Perhaps most importantly, this approach will put people with a disability at the centre of service delivery, working together with people with a disability and their families as equal partners to enable people to exercise choice in getting the support they need to pursue their own lifestyles."

The last point. "Having more choice about housing. The government believes that, as much as possible, people with a disability should be able to choice where they live, with whom and in what type of housing, just like most other members of the Victorian community."

So that's Adam's presentation and contribution to the commission. I'm sure if you have any questions, you can ask him, but that might take a while to get a response, depending. I have come here to share our story with you, but also to talk about the planning process. Because we have moved across from being a family working through with our son and then moving across virtually into an agency and then suddenly being in control of a certain amount of money and actually making it work; and then, looking at the next stage, where we have to go to the next level, whereby we would like Adam to be supported for the rest of his life and to have a meaningful life.

We didn't know how to put a plan together. We actually worked with a really good agency up in Ringwood, EACH, Eastern Access Community Health. We have done a lot of work with EACH and the people up there have got some wonderful services and are great innovators. Peter from EACH actually gave us a copy of a plan that was written up for a young lady, and we looked at that and I thought, "I could do that," so I have actually put his plan together. In putting his plan together - I'm a graphic designer and I also do work on the Internet - I thought, "This plan really needs to be accessible on line as well because that's the way of the future, it's the way of now.

I put the plan together with four key headings and I would like to put to you that these four key headings could be used with any individual with some minor adjustments in terms of how that would work, because from these four headings you can move into any other area that you require. The first heading in Adam's case is I Am Adam. From the heading, I Am Adam there are subheadings that come down that are specifically related to Adam. So it talks about Adam, Who I Am; My Disability Early Days. It gives some early history of where he is, his family and friends and the fact that he's gone into integration.

I was interested to hear the previous speaker talking about her husband who was in a car accident and how they had to start again and the difficulties with that. I believe that even a plan like this, some documentation together with families, would support individuals in that situation as well. You could take it up virtually at any level. That's the first heading. The next one, Likes and Dislikes. Everyone likes certain things, everyone dislikes certain things. Adam has a whole section just on things that he likes to do. He likes walking, he likes poetry, he likes the arts. He likes being outside in the fresh air. He does not like custard, he loves peanut butter. These are things that I'm throwing into the mix because the people that come and support Adam need to know who he is and what he requires. They can read this plan, they can see what he likes and what he doesn't like. We don't expect his support people to manage according to our requirements. We expect them to work with Adam in terms of what he wants.

They can develop a day's outing or a week's outing or plan ahead for certain things that are based on what's in this document. They're things that you can apply to anyone. The third heading is Communication and Support. Now, in Adam's case we use the word "communication" as the key heading because he actually started to communicate when he was 13 years old. He was not communicating and talking in the sense of writing until he was 11 or 13. That was the issue where we were able to get him into secondary college and able to replan his program. So communication with Adam is huge in terms of how we do that. The support covers all of the other areas in terms of self-help, active daily living, toileting, all the things that he requires on a day-to-day basis.

Of course, Adam also likes supporting - I'll read the headings - Why Communicate, Why Facilitate, Talk To Me, Culture, Creating, Writing, Art, Music, Activities of Daily Living, Health, Addressing Personal Needs, Supporting Adam and Organisations That Can Help Adam. That's a major issue in terms of opening up a whole range of things. The last one, which is a really important one, was simply called My Goals. We have two headings under that. We have Short-Term Goals and we have Five-Year Goals.

We initially started off with Long-Term goals and we thought we can't have long-term goals because governments love long-term goals because they never actually happen. We thought we would make it five years and at least that's something for us to aim for. Mind you, we have never achieved fifth year goal which is for Adam to be quite independent. We're in about the fourth year now and we're probably still at the beginning because it never actually works with the government. Despite all of that it's a good document to work from and it gives you a lot of information.

That's a hard copy of his plan. I'm happy for you to have a look at that. Some of the information is personal and I'm happy to talk to you about that. I know a lot of this is going to be put out there so we might do some slight culling of bits and pieces, but we're more than happy to share that with the committee because I think it's an important process of how we've gone about that. The web site one is a really useful strategy. I rang up DHS in the last 18 months, as I often do, and I was speaking to lady there and we were talking about one aspect of his plan, the change that occurred. Because bureaucrats operate as they do - this was about the third bureaucrat in as many months - she said, "I don't have Adam's plan with me at the moment." I said, "Haven't you got it in your file?" "Oh, well, it's somewhere there. I can't access it." I said, "Do you have a computer in front of you with an Internet access?" She said, "Yes." So I gave Yooralla as his address and within a minute his plan was in front of her - the four points that I've mentioned - and I was able to highlight those bits and pieces.

I don't quite know what she did with that at that point, but the fact that it was available immediately, she needed a password to get into that. It wasn't something that she could just simply go in, but I gave her that access very quickly. It's a strategy that we need to be using IT technology far more than we're doing and it needs to be structured in a way that actually works; not put together with a whole lot of gobbledy-gook but it needs to be simple and a process that families, individuals and the support personnel can use and work with.

MR KALISCH: So in terms of the plan that's been developed by Adam with yourselves, it's obviously accessible to him and he can update it as his goals and aspirations change.

MR COPE: Yes. With the goals - I had those in there as a Word document and that is a really important point. The goals actually aren't set in concrete. The goals do change according to where he is and how things are moving, so what might have been appropriate, say, two years ago is not necessarily appropriate now. I think that's really very important that we don't lock something in, in concrete, and say, "This is what's going to happen," and you've got that person locked in for life. So the goals must be flexible, and along with that the system needs to be able to be flexible with it. With that there is an aspect of education. All people in the system and the broader community need to be far more educated in terms of disability and people's needs than we are. For far too long we have tended to put them in the background and put them in situations where the system seems to think that it's all going to be okay.

Independence can mean a number of things for individuals. It is not necessarily living independently by oneself in the community, it may be just living away from the family home and being secure and content. This should be determined by the individual's plan and not by a formula supplied to everyone. One key aspect that my wife mentioned was the funding must be provided for the plans that have been approved. If it cannot be funded for whatever reason then the parents and the individual needs to be told and full support needs to be given so that the plan could be rewritten or reapplied in such a way that it is going to work.

In terms of the ageing process, certainly parents are entitled to lead fulfilling lives in their middle and later years. That's really very, very important. We don't begrudge any of the time that was spent with Adam but we have missed out on a number of things that other families take for granted. We only just went away overseas last year on a small holiday to New Zealand which was wonderful. I had to spend hours and hours over the phone to get additional funding for that. The interesting thing there was that the personnel from DHS didn't know Adam's plan, didn't know Adam, and initially said, "We can give Adam a holiday and put him into a centre for you."

Now, if you know Adam and you know his plan and you know where he has come from, a centre is certainly not appropriate for him and we couldn't leave him in that situation because he would refuse to take medication, he would get lost, he would put himself at risk, he would be at risk to other people because of his management problems and so on. He's not a bad kid, he's asleep at the moment which is fine, and he's wonderful, but he does have some behavioural issues that do need to be controlled and supported along the way. We did manage to get the funding initially and we did go over to New Zealand, which was wonderful, for about 12 days. But I had to sit down for several days and work out the additional funds that were needed to manage him, and he was actually able to be supported at his home for that period.

An individually funded life plan: it must be life and it must be fully funded. I'm often told that it would be too expensive to fund everyone. My response is that if you're working on an individual plan then everyone's needs are different. Some plans may be high cost, some others may only be a fraction of the cost. The cost overall would even out in the situation. If the system is going to fully fund an individual's plan then open dialogue and options must be discussed and agreement reached of the outcome. An outcome must have the individual's needs and wishes met and fully funded.

Flexible planning is important. We did at one point put a proposal into DHS. It's a table that you will have there. We said that over the next five years we want Adam to be fully independent. For that to occur it wasn't just a case of saying, "Here's the money to make him independent." He needed to be comfortable that he could actually manage being away from us. So we said, "Next year, increase the funding by 10 per cent, the following year another 10 per cent and so on," and it was a sliding scale. We were told that we couldn't apply that because the system wouldn't allow that to occur. We were told, "Well, you just simply ask for what you want now." The answer was very simple, we said, "Okay, we want 30 per cent more now then." That is absolutely crazy because they're pushing us into the situation of asking for things that we may not necessarily need. We didn't get the 30 per cent. We certainly got a lot more than we expected. We didn't get anywhere near that. The system pushes families and groups into asking for ambient plans that really aren't part of the system.

I've mentioned the funding coming from one source, which is crucial. The decision-making must be made collaboratively between individuals with the disability, supported by his or her advocate and with the family and the agency or government department. It needs to be shared, agreed on and fully understood. We need to have this partnership approach in the system.

I'm very, very aware of the fact that when we make decisions for people with disabilities in the system, we do tend to look very closely at the health model. I'm concerned that if we just rely on the health model that's not to say the health model is unimportant, but if we just have the health model as the total focus of any plan that we do, that is not going to move us down the track. It's not going to move people in the direction where they really could be moved to. Adam was in the day training centre which is a health model, and he moved into the Education Department which is a much broader based community model. I think the model needs to be very broad in that sense. You need to engage people that can give you answers in the education field and community service and a whole range of areas. I'm just pointing it up as one of the concerns that I have.

That's not to say that health is not important, it's obviously crucially important, but it can also lead you into an area whereby we tend to fix people, as opposed to looking at their real needs and actually seeing where they could be going. I've written a number of stories - in fact Adam and I have written a number of stories - on the ABC web site, The Making of Modern Australia. I don't know if I have time or if you want me to read this story. I've given you the story and I can give you the short version of it if that's the best way.

MS SCOTT: Yes, maybe the short version, unless - we are getting towards the end and I'm not too sure whether my colleagues want to ask questions but you might want to leave a few minutes for questions.

MR COPE: That's fine. I've just realised that I've already alluded to the story because the story was when we went over to New Zealand. My mistake, I'm just reading off the notes here and haven't quite got around to where we're coming from.

MS SCOTT: That's all right.

MR COPE: It does pick up on those points. Perhaps I'll read the short version of the discussion I had with this lady. This is when I rang the DHS for some support. I rang this lady and entered a discussion on process and what Adam currently has, and a list of bureaucratic requirements followed in terms of what she actually required from us; far too much information to include here. "What does Adam normally do when you have a holiday?" I was asked. "Well, we don't have holidays. Usually we have to be close to him," I responded. What I meant was that my wife and I don't have holidays together, but I did not touch on this point, it must be "old timer's" creeping in due to age. "Increasing funding on his plan is expensive and is not an option due to the time line, but we should be able to provide somewhere for him to go while you're away," she said. "Where would that be," I said, while holding my breath. "There is a facility centre down the coast where we might be able to fit him in." "That's not on, as he hates centres. Would you like to go to a centre yourself," I replied.

I was becoming agitated now and immediately apologised for the comment, remembering Bill Shorten on "It's okay to get angry but not all the time or not too often." "That's okay, I have a thick skin," was her response. "Besides," I commented, "going to a centre down the coast is not in his community and that's where he is most comfortable." I'll maybe just close on that point on the fact that it's really very important that the system needs to have a very clear understanding of what individual people require and what they want, their individual needs and aspirations that need to be met totally.

MS SCOTT: Thank you. We had a few questions along the way. John, do you have any final questions?

MR WALSH: Les, I just have one question and that is how did Adam manage in the school system and how did the Education Department meet his support needs?

MR COPE: How much time do we have? I'll give you the short answer there. In 1995 in Victoria we had an integration review which was a review of integration into regular schools for children with disabilities. At that point our family was working very closely in our own community and we managed to get a trial grant from the local region to get Adam into his local community into the local primary school of which I just happened to be the school council president. The principal was very agreeable. I suspect it was more on a charitable model, rather than an educational model but that's fine. We actually got five children into the school. This is paid for by the region. They had an integration aide and a teacher who worked with these five children independently in the school in a spare house that was on the school grounds.

Over the next two or three months an incredible thing happened. The regular teacher saw that these five children didn't have horns growing out of their heads, they were just kids after all, and they felt this was quite a challenge. They actually drew all these children into their classrooms. Adam was the last person to come into the classroom and once he was in that situation the Victorian government was at that point, through the integration program, supporting children to come through. We were successful, and Adam had a full-time aide for the next eight years or so while he went through secondary college. It took him four years to do his VCE, just a little bit longer so that he could manage the workload and so on. He had an aide fully all the time there.

I was a teacher so I worked very closely with the teachers, with the school and with the principal. It was the principal that we managed to get on side. He's a personal friend, a wonderful man, and if you can get the man at the top to truly believe in what he's doing then anything is achievable. It wasn't without its difficulties but very successful and very worthwhile and something that we don't regret at all because through that, that has actually given Adam his voice and enabled him to communicate and enabled him to learn English in terms of how it is meant to be taught and so on. He published his poetry book last year. That was called Windows and that was launched by Joan Kirner. Joan Kirner knows Adam quite well, as she would, because she was premier at that time. We know Joan as a friend. She is a wonderful lady. She came and launched Adam's book. I'd like to leave some copies of this book, if that's appropriate, with the commission, just to share and read in your spare time when you're not reading all of the other bits and pieces to maybe read a little bit out of them, some of the stories that he has to tell.

MS SCOTT: Thank you. Any more questions?

MR KALISCH: No, I haven't got any more questions. This has been very useful.

MR COPE: Have I covered the school aspect? You asked the question - - -

MR WALSH: Yes, thank you.

MS SCOTT: Thank you very much. That was a very comprehensive presentation. Thanks for both of you for coming along today.

MR COPE: Thank you very much for the opportunity and I'll look forward to the outcome, and I wish you all the best in terms of putting it together and for some final document that can be acted upon.

MR KALISCH: Thank you. Thanks, Adam, thanks, Les.

MS SCOTT: I think I've already asked twice, but just to do the final check, there's no-one that wants to come forward at this last minute to make a final comment? Okay. Tomorrow we resume here with another day of hearings. I'm very conscious that a number of people have been attending all day to listen in and observe. We return here tomorrow. I think we're commencing at 9 o'clock. If you wish to come along then you're most welcome. I now draw our hearing to a close. Thank you for attending.

AT 4.55 PM THE INQUIRY WAS ADJOURNED UNTIL

WEDNESDAY, 9 JUNE 2010