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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 WEDNESDAY, 9 JUNE 2010, AT 9.02 AM

Continued from 8/6/10

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MS SCOTT: Ladies and gentlemen, good morning. Welcome to the public hearings for the Productivity Commission inquiry into disability care and support. This is our third day of hearings. Thank you for attending today. My name is Patricia Scott and I'm the presiding commissioner on this inquiry, and my fellow commissioner is David Kalisch who is here, and John Walsh who will be joining us later. He is in modern telecommunications.

This inquiry started in April with a reference from the treasurer. The Australian government has asked the Productivity Commission to examine the feasibility, cost and benefits of a national disability scheme that would provide long-term essential care and support; manage the cost of a long-term care system; replace the existing funding - those covered by the scheme; take account of the desired and potential outcomes of each person over a lifetime with a focus on early intervention; provide a range of coordinated support options, including accommodation, aids and appliances, respite, transport, day programs 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 this area and submissions have been coming in to the inquiry following the release of an issues paper in May.

We are grateful for the submissions already received and submissions can be downloaded from our web site at www.pc.gov.au. While we would like to get submissions as early as possible, in view of concerns raised by some participants, the commission has extended the due date for initial submissions to Monday, 16 August 2010. The commission also welcomes further submissions, so don't feel you have to hold back, you can put more than one submission in.

These submissions may include additional points people wish to make, comments on other organisation's or people's submissions and results of community consultations you may wish to undertake. The purpose of these hearings is to provide an opportunity for interested parties to discuss their submissions and their views on the public record. Because we are going to be recording the material provided today, it would be very helpful if you could turn your telephone to silent or off please.

Following this hearing, and depending upon demand, hearings will be held in all capital cities through June and into July. We will then be working towards completing a draft report in February 2011 for public comment and we will invite participation at another round of hearings after interested parties have had an opportunity to consider the draft report. We will conduct these hearings in a reasonably informal manner, but I do remind participants that a full transcript is being taken. For this reason, comments from the floor cannot be taken but at the end of the day we will give you an opportunity if you wish to come forward and to 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 issues raised in other submissions and, certainly, during the course of yesterday we had a number of people commenting on things that they had heard earlier in the day. A transcript will be made available on the commission's web site following the hearings. I will just check if there are any media representatives. Is anyone from the media here at the moment? No, okay.

Safety: to comply with the requirements of the Commonwealth occupational health and safety legislation, you're advised that in the unlikely event of an emergency requiring the 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. You have probably met Ineke on the way through and there's Ralph, David and I.

I would now like to welcome David Hayter to the table please. Welcome, David. Just for the record could you say your full name into the microphone and then would you like to make a statement, please.

MR HAYTER: My name is David Hayter and I'm here at the suggestion of the Scope but I come in my individual capacity. Over the years I've been privileged in my spare time to work with many church charities and with human rights groups and refugees, and in one sense all these things have a bearing on what we do today because everything I've worked for I've done voluntarily because I believe in human dignity of my fellow people. This is what we should have at the forefront of any deliberations we have at this inquiry and also in everyday work that our agencies do on behalf of the disabled.

It's not about our agency getting more money, it's about how we can work together with the government of all persuasions and promote human dignity. I would like to quote a comment I heard on the radio recently in an interview, Bill Shorten - who you will know as the parliamentary secretary - was asked about the cost of a disability insurance scheme and he made this statement. He said, "When I was a union leader it was my job to get all I could for the public and for my members but," he said, "when I got this job and had to go out and meet the disabled, something I'd never thought about before, my whole attitude changed." He said, "It's above all cost and above all politics because we're talking about people's human dignity," and I'd like to support that statement because that is why we're really here.

Having said that I'd like to address the point of cost. I'm reading from a letter written to the former Minister for Community Services, Mal Brough, by family in Gippsland, Jenny Radford, who has given me permission to use this letter and I believe they will be making a written submission to the commission. It concerns the rule that says that carers should be only away from their care people 25 hours and no more. This family have two severely disadvantaged people with cerebral palsy and paraplegia. They have to have a hoist to lift them in and out of bed. They had one son who was normal, but because of the care that the children were having he was feeling ostracised and he wasn't coping at school and he wasn't getting help, so Jenny decided that whilst her children were away in day care that she would get a job and pay for him and they enrolled him in a private school.

Centrelink was consulted and approved it. But later on through a review they got a letter to say that she forgot to include her travelling time and she was so many points - I think an hour over the time that she was supposed to be away from her carer and they told her she could either resign her job or lose her carer's payment. In the process they had already committed to a number of payments that they had to pay and their home was in danger of being put on the market and the children going into permanent care. The reason I bring this up is because we need more flexibility in how carers are allowed to use their respite time and how they use it. When they finally did cancel her job the government ended up paying them $120 extra a week that they had saved while she was working. Also had the children been obliged to go into a home, two 24-year-old old daughters as they were at the time, I'm sure most people know it costs hundreds of thousands of dollars more to keep them in a home than it does to keep them at home.

I'd like to emphasise that we should promote to our government more flexibility in the way that what we already have is put into action, and also sometimes we think we need more money and it's probably not that we need so much more money it's that we better utilise what we already have. I think basically all I need to say, I wish to mention something that was brought up at the commission yesterday - though I was not here I've been told - that some people will know about a man called Simon Duffy in the UK who was a welfare worker in an agency with the intellectually disabled. He was called into an institution to see a client and he was so disgusted at what he saw he walked out vowing he would change the system. It took him 15 to 20 years to finalise what he wanted to do. He had the idea that if you give people their money direct into the nominated bank account - and they had to give an account of their ability of what they would spend it on, for their health and their well being - these people could be living in the community.

He joined together with organisations for the physically disabled and together they worked out a plan. He formed an organisation called In Control. If you're in control of your finances you're in control of your life. Now, I won't say too much but the point is that some people when you bring this up to agencies can only think about a tragedy that happened here when Jeff Kennett moved all the intellectually disabled out on the street and left them with no back-up. Well, this is not how this works. They have to give accountability and explain to the government or whoever provides the money that they will spend it on themselves. They must have the right back-up and support in the community. It's not for everyone, of course. It's not a one size fits all, I should point out to the commission and the government, because some people don't have the love and care that they need for it to work.

Overall, I've met Simon Duffy when he was a guest here at a conference at VALID, which is the Victorian Advancement League for Individuals with Disability, to promote this idea here. I've spoken with him personally so I know the facts of what I'm talking about. He had this idea about first he got the money from wealthy individuals and tried it, and when he could see it worked it was then he went to government authorities and councils who supply the respite care and all these things on behalf of the government and I was told at the conference - I think two years or so ago - that nearly every council, if not every council, had come on board and the government is supporting it because they know how much they can save in looking after the disabled.

Now, that could happen here but I think the only reason it doesn't sometimes is because of past bad experiences that we know about. We let our prejudice and our petty views prevent us from coming to inquiries like today with an open mind. I have found through all my work in other fields that the people who achieve most or the people they're working for are those who keep an open mind and forget their politics, their religion or whatever else and leave it at the door of such places like this so they can be open to fresh ideas and a new approach.

I will finish here by quoting what I said when I started. It's not about any of those things, it's about the human dignity of some of our less fortunate people. That should motivate every one of us, not just me, in our jobs and everything. The final outcome is for those people, not for other positions in our jobs or whatever. Thank you very much for listening to me. Thank you for the privilege of being here.

MS SCOTT: Thank you very much.

MR KALISCH: Can we ask a few questions, David?

MR HAYTER: You can if you want.

MR KALISCH: The carer payment, carer allowance dimension and the extent to which people have very severe limitations on their participation requirements, do you have a sense as to how much that should be broadened, whether there should remain some participation requirements to receive that payment?

MR HAYTER: Of course there have to be rules. Sometimes we can be so strict in our interpretation that it does more harm for the people concerned and it should be looked at in individual cases by Centrelink and by the government. Of course we can't only blame Centrelink because Centrelink are employees carrying out the government's regulations. That's one thing we should remember. When some people go into the office, I've seen them in my own Centrelink office abusing the people while they're only carrying out their duties. But it's up to the government to think about these things and make amendments so that in cases like this - in fact, I didn't finish. The young lad in question did have his fees paid through my intervention with an agency and some help from myself, and went on to not do quite as well as he wanted to do in his studies at private school, and then enrolled in Swinburne Tech in an IT course which maybe wouldn't have happened without this intervention.

I won't mention the agency's name because I don't think it's appropriate, but even when I went there, because I was not somebody who was well known or something, I was told, "You can come in, Mr Hayter, but who are you anyway?" I only hope that this is not the attitude that people would receive today, but when I pointed out that their motto was to serve the poor in the love of Jesus, which was clearly stated on the back of their annual report as a mission statement, and that two of my church members were on the ethics committee, then maybe if this is how he treated his visitors, and I'd start with him, the attitude changed and I got the help that I wanted. My main interest in doing this was not only to promote the flexibility of the rules but also because of my belief that if these people were separated and I knew really they didn't want to be, they would have cost not only more money but a whole family would have been split up. There's not usually enough respite carers, as the agencies will know, for these people to go to anyway, and the children could have been separated.

So Ian and Jenny (indistinct) allowed to have their payments paid directly and they were quite happy, you know. They didn't blame anyone. Some of the situation was caused by themselves and they're not blaming but they were just trying to get the point across that there needs to be more flexibility. They now have an accountant does their accounting work and they actually employ their own nurses. They get the same ones who the girls get used to. They are quite happy and the family are together, except this young lad, of course, has to live in Melbourne when he's studying but goes home. This is what can be achieved if we think outside the square and think about how it affects the human dignity. This is my main point that I came here, to sort of emphasise the point on their behalf because they are unable to come up from Gippsland where they live. I only heard about this when I turned my TV on one night and saw it on the news. I didn't know them personally but since I have been privileged to be invited to their home and see the love that is shown in that family and also the care is over and above their call of duty.

MS SCOTT: Thank you very much, David, for coming along.

MR KALISCH: Thank you.

MR HAYTER: That is what I think is a most important aspect that we all hope to carry in our daily lives and our daily dealings with our fellow humanity.

MS SCOTT: Thank you.

MS SCOTT: I know we have a couple of people back today that were here yesterday. We came across a USB memory stick that someone may have dropped, so if anyone has lost one from yesterday we've got it here safely. Now we have Matt Potocnik. Thank you, Matt, would you like to come forward. If you could identify yourself for the transcript. I think you're representing your family.

MR POTOCNIK: I am, yes. I'm a father of a child who has an intellectual and physical disability.

MS SCOTT: Sorry, Matt, just to pull you up. Can I get you to say your name.

MR POTOCNIK: Sorry, Matthew Potocnik.

MS SCOTT: Thank you.

MR POTOCNIK: As I said I've got a child who has a disability. I went into the disability field shortly after he was diagnosed in order to learn as much as I could about disability. I've spent about seven years working in direct care for DHS. I've given a whole lot of points to the panel this morning that seem a bit eclectic. One of them is milieu which I think the gentleman before was talking about. He was talking about environment and he was talking about the way people support one another. I was very, very pleased to see that there were a lot of very good people working in direct care and in management, but I also see a lot of barriers in terms of what people identify as good care and responsibility for people who have disabilities.

I am being critical because I am using this as my experiences in hindsight and I'm hoping to bring this sort of thing up so that the commission can identify how to change things. I'll be putting in a written submission as well but basically there's a whole variety of perspectives. I think unless you're in the situation where you're dealing with disability directly, it's very hard to really identify with difference and indifference, where you rule a line. People get caught up, they have a day-to-day job. At the end of their job they go home to a life that might be ordinary, whatever. I went home and did more direct care and looked after my son and that was my choice. But I did spend a lot of time educating myself. I saw Bill Shorten the other day at a conference and he was talking about the disability sector being an economic problem to Australia. It's an economic problem.

Again it brings to light the idea of perspective. When I get my son off the bus - I live 20 minutes drive from school and it can take him two hours to get home from school. That's up to four hours travel each day for a little six-year-old at the time. He's nine now and he still does the same travel. To take him off the bus where he's seizuring and bleeding from the nose, it's not an economic problem. It's a problem of abuse. I've been addressing this issue for probably about two years now and directed it towards the Education Department, the principal. I was involved in supporting the non-closure of Brunswick school. I respect the idea of inclusion that the 2006 Disability Act supports, but I really have to say that the bureaucratic boundaries are a disgrace.

I went on the radio, 3AW, Neil Mitchell was hosting it. The premier was there to answer questions. My son goes to school in the premier's electorate. I mentioned the school buses and said, "Up to 20 hours a week my son can be on a bus. He's got severe developmental needs. He needs that support." I asked for extra walking programs and things at school. I'm aware that there's a paper out now in regard to the funding aspects of education and how it represents education funding as the same amount to the individual, each individual.

In the disability sector where we're looking at individual support plans and supporting people from a needs base, this isn't compliant. There's a to and fro between the Health Department or DHS, and the Education Department, as to whose jurisdiction this is and who is responsible. The 2006 Disability Act is supposed to be whole of government yet the Education Department sits outside it. I spoke to Laurie Harkin, the disability commissioner, in a forum. I mentioned how my son needs to be able to walk, he needs to be supported to have as many programs to help encourage him to walk and give him that potential, and I talked about his seizures and the buses and all of that, and he stood up and he said, "I understand completely."

Now, my understanding, when someone says they understand completely, they can't accept a no for the answer. They can't not work on it. There's no way I cannot represent my son here and his needs. I have to be here. For the disability commissioner to stand up there and say, "I understand completely, but I'm sorry, it's not my job," is an absolute disgrace. I identified this about a year before the inquiry into disability accommodation services came out; that the commissioner needs broader powers; that the whole of government aspect of the disability needs to run right across whole of government, and that these bureaucratic boundaries need to be broken down. Bureaucrats need to understand the implications of having bus services like the one that my son travels on.

I've submitted questions on notice to Lisa Neville that weren't answered. I've submitted questions on notice to the Minister for Education back in August in relation to the bus travel; in relation to schools being moved out of local areas. We're talking about inclusion, whole of government. We're talking about facilities localised to the community. You don't go moving schools out, you have more or smaller schools. I asked for reports in relation to surveys they did about assessing the need for schools in the west and the north, to look at two schools. The authorities didn't get back to me. They haven't got back to other people who were involved with the Brunswick school.

Working in disability accommodation services and seeing staff-client abuse that I reported through line management: again these systems, this environment, it has been screwed down by the dollar and by people justifying their salaries and putting money in their pockets saying, "I've saved some bucks here," without identifying what the cause is; without identifying what the need is. I was the first human rights ambassador in disability accommodation services. I stood up and brought lots of things to the attention of the Department of Human Services. I mentioned how there's a separate maintenance department for all of the disability accommodation housing, how there is that sort of discrimination.

You talk about the rights of the people in these community residential houses. We talk about deinstitutionalisation. Yet we have this body having power over the CRUs dictating and law-enforcing under a non-transparent, non-accountable system. Probably the biggest things that I can say generally about what the Productivity Commission needs to have in supporting people with disability is accountability and transparency. There needs to be a voice heard from the service providers - I mean, from the service providers but from the service users, I beg your pardon.

The things that need to be addressed first I think are children, such as my son. I've actually put forward in his ISP plan that he needs to be able to walk in from school, that there needs to be staff there for when the bus gets in, or we need to have someone driving him to school so he isn't spending 20 hours of his week travelling and sitting down when he suffers from chronic constipation and he's on three anticonvulsives.

There's piles of paperwork that I've submitted to the Education Department that I'm submitting to the Department of Human Services. As a parent, to be able to bring these things forward and submit them to the ombudsman or to the Human Rights Commission is almost impossible from an emotional perspective. I mentioned the abuse in CRUs before. I'm only too aware of the systemic issues that rule the system and help support people in management to do their jobs within their quoted amounts of money. I was working under the regional manager who I believe probably the biggest asset to managing the north region area is that he's an accountant, rather than put on extra staff for a client who is having difficulty walking and falls over in the night to go to the toilet, they just put nappies on them.

I tried to get change through, as I mentioned, in relation to the client assault. I had a look at the incident reporting process and I realised that the staff incident process has a number on it when you fill out the form. The form is in a book. It has a number. You fill out the form, there's a copy for you, there's a copy for the department and there's another copy. When there's an incident at a CRU you fill out the form and then it gets taken into the department. It's at the department's discretion whether or not this gets lodged. It's at the department's discretion as to whether or not it gets looked into or dealt with.

These systems where they look at what quality represents, management of risk, there's another element in there that they look at controlling what quality is, and that's the liability and how much gets out. My son attends - I'm trying not to get him in there with the stresses of life and things - respite sometimes, a Yooralla place called Acacia Street. The only carer overnight (indistinct) one time which is a bit unusual, of course, but there were also other issues. There were a lot of people voicing their concern and it was only until a foster parent reported it to DHS that this service was not good enough and that there were real concerns that the department had to act. The reason the department had to act was that they were ultimately responsible for that child because it was under the care of a foster parent.

I mean, we have to stop dodging the bullets with these things - working in a behaviour house or a house where people have behavioural concerns where you deal with restrictive intervention which might be physical, might be chemical. I was only too pleased to see Jeffrey Chan's article and Mary Wooldridge's article, also drawing attention to the psychologist Gary Radler, in The Age on Mother's Day. I've done a lot of work with Mary in relation to trying to bring some change towards these areas. Last year on 1 July I attended a union meeting, of all things, where they had the office of a senior practitioner there, where they had occupational health and safety there, and they had workers there that work in some of these institutions - well, not institutions maybe. The really extreme ones are still deemed institutions. Staff were putting their hands up saying, "We've got no back-up. We're all alone."

The majority of the time they were talking about not being able to have things accountable to middle management. The incident reports that go off - one fellow put up his hand and said, "We've submitted photocopies of incident reports and they won't accept them." It's these hidden systems, it's not being able to complain to the commissioner about systemic issues and having to deal with an adverse events policy that's this thick, it's criminal.

MS SCOTT: Would you like us to ask some questions?

MR POTOCNIK: Yes, it might help, thanks.

MS SCOTT: I guess I wouldn't mind going back to some of your earlier issues where you talked about your son and transport problems. Are you familiar with the idea of a national insurance scheme?

MR POTOCNIK: Yes, I think the last forum that was held at the Darebin Dissemination forum where Bruce spoke, my wife and I and Jo Hine from Yooralla organised that. We're extremely proactive in disability, yes.

MS SCOTT: What's the essential problem? Why does your son have to have a two-hour trip for what you think is a 20-minute trip?

MR POTOCNIK: Logistically there's nine on his bus and there's a hoist that goes up and down. So you're looking at time factors. It takes five minutes for, say, the hoist to go down and for the person to actually get on there. If you've got nine that's 45 minutes, and then maybe half an hour driving, and if it blows out from time to time where you're waiting for the person to get on the bus where you have maybe an extra five minutes or an extra three minutes, it ends up blowing out to two hours. I think there could be a variety of ways of changing this. There could be smaller buses, there could be taxi drivers who have first aid 2 training or perhaps additional training where they can pick up perhaps just two people in a single area and drive them to school.

I think I estimated that the government probably spends about $125 a day on transporting my son to school. The two-hour limit, that goes right back to 1975 when perhaps children like my son were institutionalised.

MS SCOTT: If we had an individual assessment on his transport needs, that might result in a different outcome for your son?

MR POTOCNIK: I think quite possibly. I mean, in letters we've said we'd be interested in helping to advise towards a better outcome for the time travel periods and for the needs of the individuals on the buses.

MR KALISCH: You talked a lot about accountability and transparency, to some extent external scrutiny of arrangements. With a national disability insurance scheme or some other type of scheme that we're looking at, what do you envisage to be some of the key features that could be introduced along those lines?

MR POTOCNIK: I think all of the jobs need to be advertised and I would like to see - and I presented this to the directors at DHS. In relation to the incident reports I presented a draft that had numbers on it so that there was some accountability as to the process. I believe working in direct care - because it is so broad and the clients are so broad - there needs to be firm processes. So there needs to be a proper course that people do who are supervising these houses. There needs to be proper training in relation to restrictive intervention and what it means, not just from an occupational health and safety situation.

MS SCOTT: I think you said you were working in an area where restrictive intervention occurs. Were you provided with specialist training in that?

MR POTOCNIK: I didn't undertake training for that. Later I was offered training which was called part-training and it consisted of two-day training and it basically focused on occupational health and safety. I mean, I ended up taking a situation to Mary Wooldridge's office because I had a colleague who was having a breakdown who was supervising a house of clients who had severe intellectual and physical disabilities. A client fell on a ramp outside the CRU. They did an assessment of the ramp. Archicentre came out. The amount went into the office bill of what it would cost et cetera, middle management closed the back door. That interfered with one of the behaviour management plans for one of the clients and when he escalates - and I mean working in some of these environments they can be quite dangerous. You have people who might be banging their heads on the wall being self-injurious. You need to go and move them away from the wall so that they're not hurting themselves, things like that.

Part of this fellow's behaviour management plan was that he had access to the back yard. So straightaway you're seeing a symbiotic relationship between occupational health and safety, client health and safety. I'm still talking to Maria Batchelor in regard to occupational health and safety and the issue of trying to get numbers on incident reports, and also that issue, getting that resolved with the ramp and trying to get occupational health and safety people educated to working with the symbiotic relationships within these houses.

MS SCOTT: Let's see if I've got this right, Matt. You want positions advertised, you want incident reports with numbers on them, you want accountability through the system, who's dealing with it and you want responses back to the people who make the complaint.

MR POTOCNIK: Yes, definitely. I think it would be really good to have internal advocates independently employed working in the CRUs, working both at house level in direct care but also working, say, part of the week in middle management so that you break down some of these barriers and so that there's a bit of role modelling that can help break down some of these prejudices and poor structures. The incident report system I think would bring in a real alliance. I mean, it's going to create an enormous liability for the department and again that will be another area where we're going to have to look at improving a lot of the way that these places operate and how they support people.

MR KALISCH: You talked about the proficiency of people that work with people with disabilities, and training opportunities. You're looking at areas where training isn't available or isn't sufficient in dealing with some of the instances and preparing people for working effectively in this area? I mean, does there need to be new training developed, as well as training provided?

MR POTOCNIK: Yes, there certainly does. As far as I can understand with restrictive intervention, whereas there needs to be a focus on occupational health and safety so that the worker isn't injured, there needs to be an enormous focus on client health and safety. This is where I get caught up. I look at the quality framework and I look at the standards and I look at internal assessment and I think basically they're all rubbish and they're all words. The practicality of these sorts of things isn't upheld. The core values of the department with client focus isn't upheld. They don't have numbers on the incident reports.

I went to a client focus meeting in February and I said, "A client is going to be encouraged to vote this year," and I had people up the front saying, "Most of them wouldn't be able to vote." I had the Noble (indistinct) turn around, who runs the disability accommodation services, say, "We have to be careful not to lead the clients." I tried to get that forum that I mentioned earlier about the NDIS. I spoke to them then and there about getting a flier out through the Intranet to help attract staff to put in submissions to the Productivity Commission to come and be part of that forum. The Department of Human Services wouldn't do it. They didn't even respond to my email. I even spoke to them face to face before I left that meeting. Again these sort of barriers, you know, they're just totally, totally unacceptable.

MR WALSH: Matt, it's John Walsh from Sydney. We've heard from other people that perhaps the qualification for support workers needs to include people with an understanding and respect for people, rather than necessarily medical backgrounds. Do you have a comment to make on that?

MR POTOCNIK: My son has been often staying at Very Special Kids where they have more of a medical model. Actually we feel a lot more secure with him staying there, but I think there needs to be realistic assessments of people who have disabilities so that the actual need and level of support can be determined. Forms such as doctors' forms, the CHAP reports that go out that are an annual physical for people in supported accommodation. These forms all need to be a soft copy type form, as well as a hard copy type form. They need to be transferable and maintain the same sort of categories right across - from the CRU to the doctors. They need to be consistent. There needs to be consistency, but there needs to be understanding and empathy in relation to people who have an intellectual disability as well.

I think when you look at restrictive intervention - and, I mean, I've worked with clients who have been on what I thought - and I don't have a medical background - was medication that wasn't conducive to their behaviour or their health. I think it's important that there where people are on restrictive interventions and require specific medications, anticonvulsives, et cetera, it does need to be reviewed quite often. Often people can be on an anticonvulsive and they might have behaviours of concern and they say, "Yes, well, he had epilepsy when he was five and we keep him on it because it controls his mood." These sort of areas need to be looked at very carefully, even in terms of balance and clients falling over, how the medication is affecting them. I think it's very brief - psychologists looking at people on medication needs to be a lot more thorough. Does that answer your question?

MR WALSH: Yes, thank you.

MR KALISCH: Matt, one aspect that's been raised with us, I suppose, the influence of service providers vis-a-vis the expectations of families. I'm wondering in terms of the accountability and transparency dimension whether you see any value in moving towards individualised funding that the family and the individual has more control over the services they get. Would that be part of the solution?

MR POTOCNIK: I think that's definitely part of the solution. As the gentleman said before me, it does need to be controlled. I think this continence scheme that's come out now is just a big dodge of responsibility for the government to make it cheaper to avoid going through the continence things and to put money into people's accounts, I think it's just irresponsible. It almost sounds like to me hush money.

MS SCOTT: Can I explore that a bit more because it sounds like you were in favour individualised funding, but then you've got a concern about money going into people's individual accounts. Can you just explore a bit more why it's good in principle but you've got a concern about this in practice. What's the difference between the two?

MR POTOCNIK: George Vassiliou did a lot of work with DHS to try and sort these things out where there was a lot of money taken from - the amount of money that an individual gets, if it goes through a lot of processes, often it ends up being reduced as a result of that. I think the money needs to be accountable, and whether or not the individual who is caring for the person, or the person with a disability themselves, may need support in some way just monitoring the amount of expense and where the expense goes, and helping to establish a plan of support that the money provides. I think it definitely needs to be articulated.

There's a lot of really good things in relation to the individual support plans - minorities within the community, such as refugees and people who don't speak English et cetera who don't have the supports in their community. I think individual support plans allow you to actually employ, say, a community member that you know and trust. There needs to be training for these sorts of things to help consolidate and support minorities. There needs to be that sort of trust and value between the carer and the person who has been given support. I think just having an agency supply these people isn't necessarily the right way to go.

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

MR WALSH: No, thank you.

MS SCOTT: Thank you very much.

MR POTOCNIK: Thank you. I'd like to see ERIC introduced which was the electronic system that the Department of Human Services had been working on since 2002. I saw a preview of that. They said to me that would be introduced. I submitted a draft for the interim to try and cover the accountability of incidents and they decided not to put my draft forward. I don't know why. I've asked for a lot of information into the CID project. That was denied to me, yet I was working for the department and I even put in submissions to that. There needs to be transparency and accountability. I'll have to put in a written submission as well.

MS SCOTT: Yes, thank you.

MR WALSH: Thanks, Matt.

MR POTOCNIK: Thank you.

MS SCOTT: We now invite to the table representatives of the Summer Foundation. Can I get you to speak into the microphone, identify yourself and would you like to make an opening statement?

MS WINKLER (SF): Sure. I'd like to introduce everybody, but at the Summer Foundation we're a not-for-profit. We focus on the issue of young people in nursing homes. I'd like to introduce the people with me. Ange Barker is here and her father Ian. We were expecting Jason Anderson to be able to come today but he's unable to make it because he's in hospital. Kerry Stringer is going to just outline what Jason was planning to tell us this morning. Helen Harrington is our carers network facilitator and she's going to ask Ange and Ian some questions and facilitate the discussion if that's okay.

MS SCOTT: Yes, and you are?

MS WINKLER (SF): I'm Di Winkler. I'm the CEO of the Summer Foundation.

MS SCOTT: Thank you. Over to you.

MS WINKLER (SF): Ange and Ian are here to represent the people with disabilities in families that advise us in our work and inform our work. I guess there are three key areas that we wanted to address today. The potential of the group of people who end up in aged care, early intervention and choice. We want a long-term disability care and support system that makes the most of the potential of young people who currently end up in aged care. We want a system that provides early intervention so that people can realise their potential and we want a scheme that enables people with a disability to live where they want to live and with who they want to live and have some real choice about their living situation.

Ange and Ian are going to share their perspective and Helen is going to ask them a few questions to facilitate that. At the age of 16 Ange was nearly bashed to death by her ex-boyfriend and the result of that assault left her with a really severe brain injury. Ange spent more than two years in a nursing home before she moved home to live with her parents. Ange is passionate about contributing to society rather than being a recipient of care. She spends a lot of time volunteering. She speaks at high schools to educate kids about domestic violence, and she also tells her story to raise awareness about the issue of young people in aged care.

Then there's Ian who is going to talk to us today. For the past eight years, Ian and his wife Helen have been providing support for Ange, and I guess meeting the shortfall of the support that's not provided by paid care. They have also fought hard for Ange to receive the services and the rehabilitation that she needs. I'll now hand over to Helen.

MS HARRINGTON (SF): In the early days after Ange's acquired brain injury, many of the specialists gave some pretty negative feedback about her future potential and also questioned whether it was worth providing rehabilitation for Ange. I'm wondering if you could explain to us what that experience was like, what was said to you and also what your thoughts are about that process.

MR BARKER (SF): I've written some down here just to keep me on track so I don't go for hours. Initially we were told there was little hope. We were told by the neurologist in ICU that Ange had a Glasgow Coma Scale of 3 and would most likely remain in a vegetative state for the rest of her life and that would probably not be a long one due to complications. So we were given no hope from the start. Then as things went on, during the week in ICU a physio said that Ange would need Botoxing and serial casting immediately for her spasticity. This did not happen. She also said that she was not funded to spend much time with Ange.

When we moved to high dependency, the specialist rehabs looked at Ange and said that she could not contribute to her own rehab so they could not offer her a place. The only other choice was an aged care home in Benalla, our home town. This meant there would be no rehab at all. Fortunately, the consultant and the unit nurse manager from Melbourne Extended Care and Rehabilitation Services looked at Ange and spoke to us three times over the eight weeks in hospital, and they said they would take her even if it was only just to get her into a wheelchair so we could take her home.

The average stay there was three weeks. Ange was there for five months and given very special care by everyone. So we were offered a glimmer of hope. Over the course of her stay there she did receive Botox treatment on the ninth week and then serial casting, and then again on the 13th week. During the treatment I asked a specialist why Ange had to wait so long and we had to fight so hard to get this treatment. His answer was they decided that Ange wasn't worth spending public money on. After five months, although Ange was making some process she was still in post-traumatic amnesia and she couldn't stay in the rehab any longer due to funding.

It was suggested that Ange move to a nursing home that was in the same grounds so that she could continue her rehab on the Slow Recover program. During this time the differences in rehab was quite apparent. Those without support were still locked in their bodies and placed in front of TVs during the day. Ange with Slow Recover funding - and my wife and I to fight for her to get resources - made some progress - and the proof is in the pudding - and then as opposed to a friend's son who was thrown out the back of a ute and had similar injuries, was given Botox treatment and serial casting while still in ICU and still unconscious and was given a specialist rehab place within three weeks of his injury.

These inadequacies need to be resolved, and the hideous life-changing decisions that doctors and others in the system have to make should be removed so that they can do what they're trained for. If the doctors have the full resources to save lives it is imperative and a moral right that there should be no shortage of resources throughout their life so people can reach their full potential and contribute to society. May I also add that Helen and I have battled this. We've been working 16 hours a day, seven days a week, for eight years. For the first six years we had no respite apart from three days a year that we had to find ourselves, so something needs to be put in place. If the government are going to rely so heavily on carers they need to put something into place that's going to look after these carers. At the moment we're getting a little of support through BrainLink and a couple of other places.

MS SCOTT: Ian, how much support are you getting?

MR I. BARKER (SF):   I just had a golf day on Monday - a men's day. Helen and Ange had a women's day last year, and we had two days in March. It's very hit and miss.

MS SCOTT: Yes.

MR I. BARKER (SF):   We found a place locally in Benalla. We need some regular respite and they gave us three days in Bright in March and then they came back and said, "Well, you have to contribute 50 per cent." So even at a low rental rate that's impossible on a pension.

MR KALISCH: So do you think sort of living in Benalla is part of the difficulty or is that somewhat inconsequential? I mean if you were living in Melbourne do you think it would be any different?

MR I. BARKER (SF):   Yes, there is far better resources in Melbourne. The first time we went away with BrainLink that was a two-day retreat in Melbourne. That was the first package that the country had received.

MS SCOTT: Thank you.

MS HARRINGTON (SF):   Ange, when you were living in the nursing home, there was a point where you and your parents made the brave decision for you to move out of the nursing home and move back to live with your parents in Benalla. What were your thoughts about that?

MS A. BARKER (SF):   Well, I was (indistinct) out of the nursing home (indistinct) I was living with my parents (indistinct) yeah, to get out of the nursing home.

MS HARRINGTON (SF):   And Ange, when you moved back to Benalla, so you're saying that - what I think you were saying, Ange, is that you were thrilled to get out of the nursing home but at your age you thought that you should have not been living with your parents and that living with your parents in Benalla was your only choice. You didn't have a choice. It was nursing home or Benalla with your parents.

MS A. BARKER (SF): Yes.

MS HARRINGTON (SF): And then Ange, when you were living in Benalla you made it clear to many people that you wished you could move out of home and move to Melbourne. The options that often people gave you was living in a group home with other people. What were your thoughts and your response to that?

MS A. BARKER (SF): Well, I thought (indistinct) misgiving, yeah, because I (indistinct) live with other people with disabilities.

MS HARRINGTON (SF): What would you have preferred?

MS A. BARKER (SF): Well, I don't think I can say (indistinct)

MS HARRINGTON (SF): And Ange, I was in Benalla, a meeting with a number of people including yourself only a couple of weeks ago and there you presented to the other families and young people with disability that you wanted to live in a place by yourself in Melbourne with some supports but a place that - and suddenly - and we thought this was something that you were continually saying.

MS A. BARKER (SF): A dream.

MS HARRINGTON (SF): A dream. Since I was in Benalla just in the last fortnight you've actually had the opportunity of a place.

MS A. BARKER (SF): Exactly, yes.

MS HARRINGTON (SF): Can you describe why it's so good? What is it about it?

MS A. BARKER (SF): (indistinct)

MS HARRINGTON (SF): Yes.

MS A. BARKER (SF): (indistinct) in Melbourne I can probably get a job and (indistinct) and achieve my full potential.

MS HARRINGTON (SF): Thanks, Ange. Was there anything else you wanted to say? So you've got your own place. It's bright, it's airy. When I saw it you said it was great because you could actually get to the shops, you could get to the beach, which I was jealous of.

MS A. BARKER (SF): Yes. It's like right across the road.

MS HARRINGTON (SF): Yes.

MS SCOTT: How has this come about?

MS A. BARKER (SF): Dad.

MR I. BARKER (SF): I think due to Helen pushing so hard, Ange being involved in so many organisations I think we have - just happened straight away.

MR KALISCH: So it's - - -

MS H. BARKER (SF): I had our name down for - since before Christmas - - -

MR I. BARKER (SF): Yes. Actually, we were told two weeks ago that the public housing waiting list was 300 long, which was 12 to 18 months at least. So it was just lucky that this one came up.

MS SCOTT: Might be the case that we might ask Helen to come to the table later and - if you don't mind, just go through what you've had to do to get the support, if that's all right. You're comfortable with that?

MS HARRINGTON (SF): Also it might be good to talk about what your plan is now. At this stage Ange is not planning by herself immediately.

MS SCOTT: Okay, right.

MR I. BARKER (SF): Yes. Ange has only got a 44 hour package, which is quite a good one, apparently, but it's still nowhere near enough for her to live independently, so we have to make up the difference. We'll be transitioning her over the next 12 months or so, perhaps.

MR KALISCH: Was the housing opportunity that you've received suitable for her living arrangements? I mean did there need to be modifications or other things that needed to be undertaken within the place?

MR I. BARKER (SF): Yes, there is, there is.

MS A. BARKER (SF): Yes.

MR I. BARKER (SF): It is certainly not terrific but it's a great start.

MR KALISCH: Yes.

MR I. BARKER (SF): The place that's providing said, you know, we could get the changes made no problem. We've had our OT in to do a report.

MR KALISCH: Were there delays in being able to have those things done? I mean we have heard from other people in admittedly different states that they've had sort of long waiting times to have modifications made.

MR I. BARKER (SF): Well, I'm not sure yet. We've only just touched on that, so I don't know how long it's going to take and if we will get any funding for it. I'm fairly confident that we will, but that's an unknown quantity as yet.

MS A. BARKER (SF): I've only been there a week.

MS SCOTT: A week.

MR KALISCH: Been there a week.

MR I. BARKER (SF): Yes, we picked up the key on Friday.

MR KALISCH: Yes.

MS SCOTT: That's great. Congratulations.

MR KALISCH: All shiny.

MR I. BARKER (SF): So at the moment we're on mattresses on the floor.

MR KALISCH: Yes.

MS SCOTT: Yes.

MS A. BARKER (SF): Yes.

MR KALISCH: Sounds like sort of, yes, just leaving home, mattresses on the floor and cardboard boxes and - - -

MR I. BARKER (SF): Yes, that's it.

MS A. BARKER (SF): Yes.

MR WALSH: That's fantastic. I'm interested to know how difficult it has been for you over the years to get equipment for Ange and - apart from support just appliances and aids and stuff like that.

MR I. BARKER (SF): Yes, it's been a constant battle. I mean it's - the trouble with this it has been a battle from day one for resources.

MS A. BARKER (SF): An uphill battle.

MR I. BARKER (SF): Certainly an uphill battle. Ange got her first wheelchair reasonably quickly, I think, and apparently we were told when we asked for a new one that the turnover time was seven years, but it was completely unsuitable for Ange in four years. All the back had collapsed and her actual back was quite painful because of it. So we found a suitable wheelchair and put in an application but we still had to wait 18 months for it and her back was quite severely compromised, you know, waiting that length of time.

MR KALISCH: So how do you think Ange's life course would have been if she hadn't had yourself and Helen to fight for those resources and obviously have the capability to deal with organisations and advocate on her behalf?

MR I. BARKER (SF): Well, initially the only thing we were offered was an aged care facility in Benalla which was full of dementia patients, so that was - I just immediately said no to that. We were offered that two or three times over the course of time. I think if she had have had early intervention, had have had that Botox and serial casting initially, that would have been quite a different outcome. She would have had far less pain and discomfort throughout her - rest of her - - -

MR KALISCH: Recuperation.

MR I. BARKER (SF): Yes. As I said, you know, the difference was, in comparison with a friend of ours whose son was thrown out the back of a ute, he was in a specialist rehab facility within three weeks while he was still unconscious. He was able to do standing transfers in four months and, you know, was able to balance and things like that. It may have been due to his injuries, it wasn't quite as severe as Ange.

MS SCOTT: Could it also have been because it was in a car, associated with a car, that he was under the TAC - - -

MR KALISCH: It was a TAC - - -

MR I. BARKER (SF): Well, he definitely had the treatment there.

MS SCOTT: It would have been funded by TAC.

MR I. BARKER (SF): Yes.

MS SCOTT: So it was funded by TAC.

MR I. BARKER (SF): He was funded by TAC.

MR KALISCH: Yes.

MR I. BARKER (SF): And, you know, that goes against the grain because he was doing the wrong thing to start with.

MS SCOTT: Yes, I understand. So in effect if it hadn't been Helen and your care outcomes would have been radically different?

MR I. BARKER (SF): Well, yes, Ange would have gone to the aged care nursing home. She wouldn't have received the Botoxing.

MS A. BARKER (SF): I would have been twisted.

MR I. BARKER (SF): Yes, she still would have been twisted, locked in her body.

MS SCOTT: Yes.

MR I. BARKER (SF): Probably remain that way and not able to communicate.

MS SCOTT: Certainly not able to talk.

MR I. BARKER (SF): Yes. Yes, the nursing homes don't offer any rehab at all.

MS SCOTT: No, I understand.

MR WALSH: What is the - I mean it sounds like things are looking up now. What are you hoping to do from now on, Ange?

MS A. BARKER (SF): Well, I now (indistinct) I have (indistinct) and be able to (indistinct) with the shopping and (indistinct)

MR WALSH: Thanks.

MR KALISCH: I suppose the one question that does intrigue me a little bit is obviously the first advice you received about early rehabilitation was quite negative - - -

MR I. BARKER (SF): Yes.

MR KALISCH: - - - and not very encouraging, but obviously something changed at another stage. I mean were there other rehabilitation specialists that then saw the opportunity and the need to intervene?

MR I. BARKER (SF): That was a problem, because we got that negative news to start with the specialist rehab wouldn't accept her. It sort of cut off any funding and any assistance. But once we got into the Melbourne Extended Care they had only been used to treating amputees and stroke victims. They had never had anyone like Ange. They had a whole house meeting, even the cook, yes, because Ange was only 16 at the time. So they had a whole house meeting to decide to take Ange on. They decided to and because they knew they didn't have the expertise they sourced expertise.

We had John Olver came in, who is a rehab specialist from Bethesda. He suggested that Ange might need a baclofen pump placed in like - it's like a pacemaker that sends off medication to stop the spasticity. So we didn't believe that was right. So we found - the consultant went to the next or the expert on Botoxing, and that was Barry Rawicki. He said that he didn't believe Ange needed a baclofen pump and in fact he didn't think that Ange needed most of the medication she was on. So then we went back to the rehab with that news and it took about four months for them to finally to get Ange off the medication because they, you know, were very hesitant about it because they were in unknown territory, really. Once she did come off the medication she started to wake up and do things. Because we were there one of us were always with her. We also have a son. So we used to do - changed week about. I think we did - we used to do about 60,000 K's a year going backwards and forwards and 12, 16 hours a day with Ange. Because we were always with her, particularly Helen, she would take her out shopping, take her on train rides into the city, just treat her like normal.

MS A. BARKER (SF): And dad would (indistinct)

MR I. BARKER (SF): Yes.

MS A. BARKER (SF): Yes (indistinct)

MR I. BARKER (SF): So she'd offer ice cream, go down to the kiosk and have coffee and things. She'd offer Ange a lick of an ice cream and one day she took a bite. She was still on tube feeding and everything and so she told her friends this. We were at home one weekend and her friends came down to visit and we found out about a month later that they brought in a McChicken burger and given it to Ange to eat out on the grounds. So after that - after we said that Ange was eating and we were always pushing the speech therapist, we had to sign a paper to say that if Ange died it was on us. So we were quite happy to do that. We were always pushing the limits, which was what you need to do.

MR KALISCH: Yes.

MS SCOTT: Yes, great tenacity. Well, thank you very much. Helen, thank you very much for coming forward.

MS H. BARKER: Thank you.

MS SCOTT: We're looking forward to hearing from you about how you were able to progress through the system. I guess maybe how an insurance scheme or an alternative or better scheme would have made a difference; you know, the things that you're looking for for the future.

MS H. BARKER: First of all, I'd like to say that if it hadn't been for Slow to Recover, which is just in Victoria, it would have been a lot harder work for us because we wouldn't have gotten a wheelchair, we wouldn't have gotten anything for An. So that has been a big benefit and I really feel for people in other states who haven't got that. With An, I constantly fight every day trying to get things for her, and she said she wanted to go to Melbourne. So I've been just chasing up housing organisations and requesting the DHS, just applying and ringing up people and asking if they know of anyone or any other housing organisations, and I was lucky enough to find one that has come through, which was very good.

But I fight constantly for everything each week for her, just to make her life better, because I believe that if she had been in insurance of some sort she would have been able to gotten better rehab at the start, which would have made a great deal of difference to her now. With coming off the medication, she started to ring the bell; here was this girl who was supposed to be in a vegetative state for the rest of her life. We got the advice from Barry Rawicki - who said she wouldn't improve as well, and so did John Olver, they both said that she would never get any better, but they didn't think she needed medication, and that I, as a mother, would one day come to that realisation.

I said, I don't think so - and when he said to stop the medication and she'd come to life, I mean, if you're going to live you've got to be alive and be out there living it, so my next plan was just to make sure she gets a life and to keep working on that. When I'd take her shopping and everything she couldn't even sit up, you weren't even sure if she was really able to understand what you were doing. But if you're going to be alive you've got to be out there seeing what is happening in the world, to entice you to get back to it. So I spent that time, and then moved to Melbourne. There's something she wants to do, so it's got to happen for her. So we just keep working away at every little problem until we get through them all.

MS SCOTT: The 44 hours of care that you've been able to wangle out of the system, you're saying that won't be sufficient. So how are you initially going to structure things, do you think?

MS H. BARKER: At first we're just going to stay with her as much as possible, and then take her home to Benalla when we want to go home for a break and that. It's not perfect, but it's what we're going to try. She says she'll be able to live alone eventually. Hopefully, I will be big enough to let her do this. She has got her first flat, and it is near perfect, it's only a rail or two that's wrong. Everything is great, and I'm feeling very confident that I'll be able to let go. Being a victim of crime, I do have that, because he lives in Melbourne as well, I don't know where, but I have got to be strong and let go of that. I've got to make sure she feels safe.

But once I can tick all those boxes, and she can get herself in and out of bed properly - well, she can do it, but a little bit faster would help me - then I'll maybe step back and let her have a go on her own, with just the 44 hours of care; because we can't be there forever for her, so if she can get a life and get happy and get a job. She does a lot of work with domestic violence and she does a lot of work with the Summer Foundation and young people in nursing homes. Hopefully, she'll get some more work and be able to make a living out of it, which she wouldn't have been able to if she'd stayed twisted up in a nursing home for the rest of her life.

MS SCOTT: No. I understand.

MS H. BARKER: She wouldn't have contributed to anything, would have only been a burden on society. Already she has spoken to probably six, seven thousand students, and we have had some very good feedback from them. So she might have only saved one life there, but it might be worthwhile.

MS SCOTT: Yes, I'm aware of Ange's work on domestic violence. So the message has spread far and wide. Well done.

MR BARKER: An was part of the federal government campaign.

MS SCOTT: That's right. Domestic Violence - Australia Says No; I remember that very well. John, have we exhausted the questions?

MR WALSH: Yes, thanks very much, guys.

MS A. BARKER: Thank you.

MS SCOTT: Thank you for coming here to day, all of you. That's great.

MS WINKLER: Thanks for the opportunity.

MR ANDERSON: Thank you.

MR KALISCH: We'll just resume. We welcome Shaunagh and Wayne Stevens, to present their evidence. If you could state your name and in what capacity you're presenting here today into the microphone, just for our recordings, and then also, if you wish, to make a short opening statement.

MS STEVENS: Hi, I'm Shaunagh and I've come here today to put a personal face to the problems that people with disabilities face. I have concerns about the present structure of the NDIS and they come about partly because I'm associated with an advocacy group, disability group. From the start we have been concerned about the reference to this scheme only covering profoundly disabled people. I believe that this scheme should cover anybody with a disability, not just profoundly disabled. I think that it should be on a needs basis and a vulnerability basis.

The reason why I say this is because labels have prevented me from getting into things. I have been classed as too disabled to get funding at the moment because they're not doing large packages. Then in the next breath I'm not disabled enough to get into this program or that program. Quite frankly, labels to me, I hate them, and I have tried to steer clear of them. I never even used the word "disabled" or "impairment" to describe myself up until I had a car accident, a drunk driver hit me, and that's when my life changed.

Up until then I did have a disability but I was functioning quite well. But then I had to go into a wheelchair, and that's when my eyes were opened. When I was vertical I had a lot more respect. As soon as I parked my backside into a wheelchair, the way society treated me and the way that I was shunned and excluded just blew my mind. I had no idea what people in chairs had been facing all their lives. So from that moment on it has been a driving force of mine, and I do have hope that society will change and that it will get better.

But it takes people to come out and speak about the atrocities that are still going on in a country that is one of the richest countries. People are still travelling in goods van because they can't get seats on trains. I have had instances where there has been months where I have had to sit soiled in my own urine because I couldn't get anybody to help me until somebody would come home and change me. We only get four hours of help a week, and with those four hours there are very strict, rigid guidelines that we can use them for, so therefore they will say, No, we can't do that to help you," "No, if it's classed as respite, we can only do" this, this and this.

But for us, respite for Wayne meant that he got his four hours away from home, but then he had to come home and do all this stuff, because the woman that was sitting beside me wasn't allowed to put out the washing, she wasn't allowed to sweep the floor, because that was classed as home duties. So we want it to be more flexible and this scheme to have flexibility and not be so rigid and realise that if somebody needs respite they actually need somebody to step in and do exactly what they would be doing in those four hours so when they come they don't have to stay up till 1.00, 2 o'clock in the morning trying to get the washing done and trying to get the kids' clothes ready for school the next day and all the stuff that Wayne has had to do for me over the last 10 years when my mobility and my health has deteriorated.

From this car accident I lost the ability to be able to urinate and found out that I was allergic to a lot of antibiotics. So every time I've got a UTI I had to go into hospital and you're put on harsh drugs. That's the other thing with this, you can only be away from your carer for 60 days. When I'm in hospital Wayne actually has to do far more work because he has to travel in and out to see me; and I see doctors in the city, and he quite often has to come and advocate on my behalf as well, because when you're weak and vulnerable they don't listen to you.

I am forthright in what I need, but when you're not feeling well they still don't listen to you. The frustrating thing is he comes and says the same things that I've been saying and they listen to him, but they won't listen to me. I have to go to my doctors through the private sector because that's where they operate. In the public sector when you leave hospital you get outside help and it's all teed up before you actually walk out the door, but with the private sector you get pushed out the door and then you have to make all these phone calls when you get home, and it's a month before any services get put in place. I was in the position where I couldn't walk, I couldn't transfer into my wheelchair properly and I was incontinent and wet the whole time, and this went on for three months.

I got extremely depressed, and that was the only time that I thought to myself, "I'm living in Australia and yet I'm reduced to this." We'd rung everybody and we tried to talk to people and say, "Can you help us?" "Can you help us?" and they kept saying, "No", "No." In the end one of the strategies I used was my father would come down from Darwin every time I needed to go into hospital, when my children were babies, and he would come and stay for eight weeks. They would give him assistance because he was over 65, but they wouldn't give me any assistance, because I had an able-bodied husband who could pick up the slack. I said, But he's not home. He's off working trying to pay for my wheelchair-accessible home.

So I have hope that this new system that they're trying to put in place is going to prevent people having to suffer demoralising situations where they are forced to sit in their own excrement and they can't do anything about it. I'm hoping that my beautiful husband, sitting beside me, will get some assistance in the form of respite that will enable him - at the moment any hours he doesn't use he can't accumulate them. We live in Beaconsfield now, but when we were in Traralgon he could accumulate the hours and it was fantastic, because when he was at his wits end and things were stressing him out he could just say, "I've got X amount of hours," and he could take himself away for the weekend and he could do something that he wanted to do for himself. One of the things that he did was to go on the - what was it?

MR STEVENS: Arthur's seat.

MS STEVENS: Arthur's seat chairlift, because I couldn't go on it and it was something that he always wanted to do, so he took himself off for the weekend and he did that. It recharged his batteries and he came back a new man and we forged ahead. Again, I'm a person too that has spent a large majority of the last 10 years locked up in my house because I don't drive any more since the last car accident. I don't have any assistance to get me out in the community. I need somebody to go with me because I can't change myself from the waist down and if I have an accident I don't want to be sitting in my own excrement for three hours or whatever it takes for me to get home.

MR STEVENS: And the taxis are awful up here.

MS STEVENS: And the transport is terrible. I haven't caught a train since they put me in the goods van. The system is at the moment is that you've got to go way down the other end of the platform, sit on a yellow line so the driver knows that he needs to bring the ramp out. Then you go into the only carriage that is accessible. What you'll find is all those seats are full. Then it is up to the person who has the disability to ask able-bodied people to move. Sometimes it's not uncommon for you to be told where to go and not so nicely, and the driver says, "Got nothing to do with me," and he'll just go off and drive his - and I refuse to put myself in that situation because no-one should have to be subjected to that. So I don't catch public transport. So I stay home a lot.

I'm very lonely. I haven't been able to make friends where we live because I haven't gone to parent meetings or anything like that because of my situation. The only thing that's saving my sanity is this year I joined the leadership course, which has been fantastic for me. I also started up doing a community development diploma because I'm very frustrated at the length of time it takes for any change to be implemented. I didn't understand the system and I thought by going and doing a community development course it may allow me to understand the system a bit better and reduce my frustration and also make me a better advocate for change, because it is very difficult for me to not get emotional and be - get a bit aggro at people's lack of empathy, sometimes. You know, I've lost it a few times and this leadership course is teaching me to approach things a bit differently.

Again, all I wanted to do was put a personal face to 48 years of having a disability. It hasn't been easy but there's been benefits along the way. I've got a beautiful husband and two beautiful daughters and I want them to see that we are - people with disabilities have benefit and are seen as productive members of society because sometimes what they see is that I am treated terribly. They want to change that too. A dream of my daughter's is - she has just started doing a SEDA course. She wants to start a ranch and have the buildings all accessible and just have a ranch for school age kids doing sport activities, but have it all accessible so that if kids with disabilities want to come along they can; because she has even noticed at 15, there's nothing much out there.

Physical access into the environment is a big issue. The government started talking about access to premises in 2000. It is now 2010. Yes, they have been tabled but how long is it going to take it from the table to actually being out in the community and making a difference? Anybody's guess, because that process can take a lot of years as well. So I just hope that what comes out of this is that people - funding becomes more needs basis and that people with disabilities get a choice of where they put their money to get their service, because in my situation with the HACC funding I have to go through the shire. The shire has subcontracted out to an organisation that doesn't understand people's needs with disabilities. They have been a nightmare to deal with. They have come into my home and threatened me. They have forced me to sign blank pieces of paper which are supposed to be my action plans, in the name of doing the right thing by me and saying if I don't let them in the door they're going to withdraw all my services. They have rung me up and said, "You have to do this, this and this," and I say, "No, I don't." But Wayne will testify that I've got to the point that I will not have them in my home unless someone is present because of what they've done to me in the past.

This is an organisation that has the responsibility of providing HACC funding for the whole of Cardinia. It is known that they aren't terribly good with people with disabilities but they keep getting the tender and they keep rolling on. I can't say to them, "Goodbye, I'm going to go elsewhere, somewhere that's going to treat me with respect," because I don't have that option. I have put in complaints to DHS. I have put in complaints to the shire and they just go on deaf ears. That is another concern of me that the present NDIS doesn't ask of the services why - you know, "How can you improve your services? What's wrong with your services? Why are these people - are there people out there still so unhappy about the services they're receiving?" That concerns me because from where I'm sitting the NDIS is service driven. It's not really driven - it didn't start off with people with disabilities behind it.

The other thing that I'm concerned about is advocacy. Advocacy has a great part to play in services for people with disabilities and yet the government doesn't seem to think advocacy is very important because they tried to get rid of it in 2006. I think that advocacy should play a big part in this whole rearrangement of services because it gives us another avenue to have a voice. If an advocate is working for you, you know that they have your best interests at heart.

MR KALISCH: Shaunagh, would you mind if we asked a couple of questions?

MS STEVENS: No worries.

MR KALISCH: I don't know whether - Wayne, whether you want to say anything?

MR STEVENS: I'll be pretty brief. But as a carer and husband of Shaunagh for 18 years I've seen a lot of things happen to her. One such issue was with a hospital where again they don't listen to her. She needed a particular appliance but she had trouble with it and she said can she try something else before she left hospital. They said, "No, you've got to try this appliance." After five extra weeks they gave in when she really had to crack it and make a big scene and they said, "Okay, we'll try this new appliance." She was home the next day. So people just don't listen. She's an expert about her own body. They are just so dogmatic. They will not listen. They won't do things for other people.

The health funds, they put pressure on the hospitals to kick patients out of hospital. Shaunagh has been sent home early. She's been sent home without - they've said, "Oh yes, we've got things linked up for you" she gets there the Royal District nurses says, "Oh, well, we haven't been told about," or, "We have to do an assessment before she can get our services." So it's red tape. It's not linking up and, you know, being sent home without what she needs, the equipment, is just ridiculous. The health funds have forced her to go from rehab - where she needed that rehab, the specialist said she needed rehab, physio and everything like that - the sent her to an aged care facility because it was cheaper. That's all they look at. They look at funds. But in the long term it actually isn't cheaper. I've worked in McDonald's, which is very dollar focused. You know, squeeze the last cent out of a pickle. Yet it doesn't make sense, short term, to kick someone out of rehab early then she ends up for rehab for a longer period of time. It doesn't make sense either way but they're very short-sighted and they want to make money, they don't care about the person.

Then there's issues like care. A couple of years ago I was working and there was a conference I could go to. We found out - it was carer respite centre. There was a 20 hours one-off block available for once a year for things like that. We said, "Well, I didn't know about that before. How come you haven't told people?" The answer was, "Oh, because then people would use it." To me that will be great, not just having my three or four hours once a week but every now and then if I needed that extra break, whether it's for going to attend training seminars or just have a break. But no, it's something that's kept hidden because you might want to use it.

Now, that doesn't make - again for them I think knowledge is power and they don't let you know - Centrelink won't let you know things. You fill out a form to apply for a pension and this is what you have to do. You ask them. They say yes. A week later you get a letter in the mail saying, "Well, you haven't got the pension granted because you haven't filled out this form." You go back, you ask again. "Is there any other forms to fill out?" "No, just this one." Same response, you get another letter. This goes on for months. You haven't got a job. I haven't had work for the last 18 months because my contract finished basically due to government funding cutting a three-year contract, it lasted eight months.

So now I've been trying to get work in other areas and it's very short-term work, it's very hard because of Shaunagh's needs that I have to be there for her and so I can only work part-time. It's very difficult to get part-time work. With Centrelink with a carer's pension the maximum you can be away from your partner is 25 hours. They don't allow for travel. So I worked it out if I had to travel three hours a day, which some places you have to, you can only work 10 hours a week. I don't want to be too far away in case she does fall over or something happens. It's not a simple matter of she's just recovering from a broken leg. She has different issues. She has been hit with different illnesses over the years and it's unpredictable. At the moment she's been quite well but they're the sorts of issues that I'm faced with.

Then last year I spoke to the doctors, "Look, I need more respite. What can you do for me?" "You're the expert, you'll know." "Well no, what's out there? Can I get some more respite?" because I was at the end of my tether. I only found out a few weeks ago when I went for a check-up that my blood pressure last year was 180 over - - -

MS STEVENS: 184.

MR STEVENS: Yes. Now, normally it's about 120. I was under stress but the doctors and nurses didn't do anything. I'm thinking, "So they're going to wait till I keel over then they'll put in some services in place." That's too late. I just need some support for me and the number of times when I was working the hospital would ring up and say, "Shaunagh can come home. We're discharging her." Shaunagh wasn't feeling crash hot but she wanted to be out of hospital in a home environment. So I'd leave work. I'd ask for time off. I'd get into Melbourne, go to pick her up, get up the sixth storey level, grab all her gear, put it in the car, come back to pick her up, a new charge nurse came on shift, looked at Shaunagh and said, "Where are you going, because you look like," you know, "You look terrible. You're staying." So I went and got all her gear from the car, brought it back up and put it in the room and then drove back to work. They said, "Oh, Shaunagh settled in at home?" "No."

Now, these things happen all the time and Shaunagh's on the phone because they're threatening to kick her out of hospital and do this and do that and the stress for me. I'm trying to keep calm and keep her calm and wondering what's going. She can't go home until she has got a new scooter or wheelchair and I'm having to take time off from work or duck in after hours to go and pick up some supplies for her because they haven't got them there, the hospital doesn't provide them. I have to find where they are. So all those things are putting pressure on me but no-one really worries. In fact my last - two employers ago we ended up taking them to court for unfair dismissal because they were putting me under pressure, wouldn't let me cut my hours to look after her, Shaunagh or my family.

MR KALISCH: Okay. John, do you have any questions?

MR WALSH: Thanks, Shaunagh and Wayne. Shaunagh, I'm just interested, I think - I'm interested in how you got into the support system after you had your accident. You said it was motor vehicle accident. I'm just wondering whether the (inaudible) involved at all.

MS STEVENS: Sorry, you cut out.

MR WALSH: I'm sorry. I'll just talk up a bit. Can you hear me better now?

MS STEVENS: Yes.

MR WALSH: Yes, okay. I was just asking about when you first had your accident what supports were available to you then. Was the Transport Accident Commission involved at all?

MS STEVENS: Yes, it was, but they put me through hell for five years because they kept saying that what I was going through was indicative of my disability. It wasn't the car accident. So one minute I had services, next minute I didn't. I spent two years practically laying on my back because of the nerve damage in my back and my mobility, my ability to urinate, all went out the window. So I took - I started a journey that I never anticipated taking. So TAC were absolutely horrific to deal with.

MR STEVENS: They're an insurance company. All they're interested in is saving money. Every time Shaunagh changed her tablets and would put in a claim they'd say, "Why do you need those tablets?" Well, it's for pain or back pain or whatever and because it was CP they'd say, "Oh, not normally. We're not going to pay for it until you get another doctor's report to say you could." Or every week they'd send us a letter saying - because at this stage our girls were only about two and four and so TAC were providing some care. I was trying to work again to pay off the house. They said, "Okay, if you don't give us some new information from your doctor about why we should keep paying for care, we will pull the pin on that." So we were always - every week something might happen that they would change. They were trying to blame everyone and say, "Oh, the responsibility for payment and services should be with the local council," this, that and the other, "and not with TAC." They kept using the excuse, "Oh, we reckon it's because of your CP, your pre-existing condition that's caused this," even though she had no problems before the accident. But that's what they did and they did it all the way along. We got a modest payout because - we couldn't get more because we'd been going for five years. Our solicitors said, "Look, you can go for - - -"

MS STEVENS: Our parents were terminally ill at the time. My health was suffering. So I took the - I settled because I needed it over. Five years of hell was enough. But I wanted to see it through but I just couldn't do it because being supportive for my father and Wayne being there for his mother - and my girls were losing their grandparents. That took precedence over what TAC were doing. I needed them out of my life. I needed to cut my stress.

MR WALSH: Thank you.

MR KALISCH: The issue you talked about was about having flexibility.

MR STEVENS: Yes.

MR KALISCH: And having sort of obviously assessment based on need and then sort of receiving some support but then having the flexibility to be able to use it how you believe it's going to provide maximum support.

MR STEVENS: And consistency, because up in Traralgon I could roll over those hours. If I wasn't playing tennis for one week because there was holidays or I was sick or the carer wasn't available - whereas down in Cardinia that's not possible. So there's no consistency. Of course we didn't know that till we came down here but you can't change anything because we had to be closer to Melbourne for the specialists that Shaunagh could see. So, you know, that made it very difficult if they said - and also, "Well, you can't do ironing, you can't do this, the carer can't do that." So while I'm away playing tennis and hoping to relax I've got back - I still had the same sort of stuff to do.

MR KALISCH: Same jobs to do.

MR STEVENS: The other thing is they really put it - it's exactly three hours. So if it's - and I was playing night tennis, I think 7.30 till 11.00 at night. They said, "If you're not back by 11.00 the carer is going to leave." So the kids were about six and eight. You know, the carer at some stages was basically waiting in the car outside ready to go. I said, "Well, I can't tell my team halfway through a match I've got to go. How is that going to help my health?" You know, a bit of give and take because there are other nights that we finished early and let the carer go early; but no.

MS STEVENS: The other thing too is I wake up every day not knowing how my body is going to behave, so I have to take it as it comes. So it's very hard for us to establish a pattern with rigid rules and guidelines because we need to be able to have a flexible arrangement whereas, okay, I'm bedridden for a couple of days because I'm so spastic that my body is not allowing me to do anything. So we need to change the arrangements a bit. But in the present system you can't do that.

MR KALISCH: Are there any sort of features or characteristics of staff that you've had sort of working with you that gives you a sense of these people are more equipped or better able to assist? Are there particular qualifications, particular perspectives, attitudes on - what seems to make a difference?

MS STEVENS: I have two carers at the moment that - I went through quite a few and I - they like coming to my house. I love them being there. Basically they're approachable, they treat me with respect. You only have to show them once what you need and they go and do it. I've had other carers that come and you tell them what you need, and I'm not a person that wants to watch everything they do, like, instances where I've asked them to change my children's beds for me or change my bed; she had changed my bed okay, but when it has come to the kids' beds she has just straightened up the doonas and taken the clean sheets and chucked them in the wardrobe. I didn't expect a carer to be behaving like that.

What breaks my heart too - I've spent a bit of time in respite, so I get to speak to a lot of elderly people - is the stories that they tell about the treatment that they receive; and they don't buck the system, because they're scared that their services are going to be taken away, because that's what in Cardinia they tell them. I've been told I'm blacklisted because I kick up a stink when I don't like what they do to me. I said, "You can blacklist me all you like. If that gets you to change your procedures, it was worth it."

I have been told that carers just go and sit and have coffee for two hours, don't do what they're meant to do, and then get them to sign the bit of paper and off they go, and this has been going on for a long time. I have said that to the company that Cardinia has subcontracted out, and they said, "We can't do anything unless we get complaints," and I said, "Well, you know they're not going to make complaints." The other issue with them is I wasn't happy, so I asked to have a round-table discussion to try and sort some stuff out, which they said they would do; that was two years ago, and they haven't rung me back.

They rang me back in January of this year and they said, "We want to come in your house and do an assessment." I said, "Well, you know the answer to that. You can only do an assessment if I have somebody present in the house, because of the past treatment that I've received." I said, "Also, you're not coming back into my house unless we have the round-table discussion that I was promised two years ago." She said, "I'll get back to you. I haven't heard from them again. So they tell you the procedures, but they don't follow them anyway.

MR STEVENS: There's also restrictions on other providers. When I was working and Shaunagh had to get to medical appointments there was a volunteer patient-transport scheme available and they had guidelines such as the last appointment that Shaunagh could make in the city was 3 o'clock because the drivers had to - - -

MS STEVENS: No, they had to be out of the city by 3.00, so the latest I could make an appointment was 12.00 or 1.00. As I tried to explain to them, when you get a specialist appointment, you can't say to them, "I've got to be out of your offices by 1.00," because they're going to say, "You're out when you're out."

MR STEVENS: Then they even threatened to pull out services for Shaunagh, because one of the drivers who took Shaunagh said, "How did things go?" Shaunagh said, "I just got another appointment for tomorrow," and he said, "I'm available," and so he then ran it past - - -

MS STEVENS: I rang up the voluntary transport coordinator and I said, "I'm not well. I have to go back in for another procedure tomorrow. Reg has said he's available. Can you get back to me, please?" The next minute I get this big long letter from the committee of management saying, "How dare I take it upon myself to organise transport? There are set procedures to follow," and if I continue to organise my own transport I will be not able to use this service again. So I wrote them back and explained what I had done. They called Reg in and hauled him over the coals over it too, and he explained what had gone down.

The problem was that this woman only works Mondays and Wednesdays. I went in for a day procedure and then was told I had to come back for a day procedure the next day. Reg knew that it was going to be very difficult to get hold of her, so he said he'll try and organise it. We were trying to make her job easier, and instead it backfired on us. The same organisation that provides for HACC funding also does transport. They're the ones that say, "You've got to have appointments no later then 1.00 because our drivers have to be out of the city by 3.00." I said, "That's too restrictive and it makes it too difficult," and they said, "Well, don't use our service then."

MR KALISCH: John, anything?

MR WALSH: No. Thanks very much, Wayne and Shaunagh.

MR STEVENS: Can I just make a note about access. I mean, I know that mightn't be totally covered. But if we go to a hearing like this we want to make sure it is accessible, and even the toilets here, the disabled toilets, aren't fully accessible. I don't think Shaunagh could get in by herself, because I have to hold doors open, they have a very narrow doorway. There's no disabled parking out the front or anywhere. So things like this have to be considered when you're holding an event for people with disabilities.

What I'm finding is, even with planning, you go to an event like a sports event and they don't have it accessible. My wife wants to go there to enjoy the time with the kids and she can't get there, for whatever reason. Systemic change isn't available. For example, you go to a store like a Kmart or whatever to use the change rooms and they don't have a disabled one, you manage to get that one changed, but they don't automatically change the ones in all the other stores. So if you have to go to another store or you move towns, you've got to go through the whole thing again and again and again, so it keeps popping up.

What is really disheartening is when you have got new buildings that are supposedly accessible, and they're not, or they change them to make them less accessible, and that also happens, there's always barriers there and you have to change the attitude of the people still. Managers as well as staff, because the managers sometimes don't care. I have been booked and had my car towed for parking in a disabled bay in Latrobe Street because it's a clearway after 4 o'clock. I have never heard of it before. The council said, "Well, stiff. These are the rules."

I said, "Has anyone been booked for parking there before, because, you know, I saw the disabled logo, that means I can park there." "Oh, well, no-one else has been caught like that." So I rang up the Disabled Motorists Association, "Yes, we have heaps of calls." So again it's about power, what they tell you and what happens; and they haven't waived it, we're waiting on the mayor and the CEO to look at it. But a disabled parking bay becoming a clearway?

They're trying to make, supposedly, Melbourne more inclusive. In fact, it's worse. Disabled bays, instead of having nice wide bays where you can open both doors on each side of the car, they're making them half as big, because it's a minimum standards rather than having at least a certain number of bays wide enough so people can get in and out. So they're trying to do this harmonisation parking scheme; it looks again like it's not about helping address the needs of the person, or the person with a disability but trying to save money for the council or the government.

What we're concerned about with NDIS is they're looking at it from the service-provider point of view, how they can make sure they have got funding and either can save money or gain money. and not actually provide service to persons with a disability and how they are going to be assessed and their eligibility. We have had that issue with the TAC impairment table, "You're eligible," 'No, you're not," "Why? Our doctors, our specialists say you're eligible," and then TAC, their doctors are employed by them, they're going to straightaway say they're not eligible. So if we're going to have an eligibility criteria and it's done by experts, it must be done by people independent of the funders as well.

MR KALISCH: Thank you very much for your time.

MR STEVENS: Thank you.

MR KALISCH: Now we have UnitingCare Community Options. Would you like to, for the record, indicate who you are and on what basis you're presenting. Then if you'd like to make a short opening statement.

MR SHEPPARD (UCCO): We're here on behalf of UnitingCare Community Options. I'm Scott Sheppard.

MR CHAPMAN (UCCO): I'm Eddie Chapman, the policy analyst with UCCO.

MR KERR (UCCO): I'm Angus Kerr. I'm a team leader in the disability team.

MR SHEPPARD (UCCO): Susanna Laurens was down to present, but unfortunately she had a family emergency, so she couldn't make it. Thank you for the opportunity to come and present to the commission today. Hopefully you're aware we have provided a brief submission.

MR KALISCH: Yes.

MR SHEPPARD (UCCO): I'll hand over to Eddie to summarise that and give you a bit of background, and then we're happy to answer any questions that you might both have for us.

MR KALISCH: Thank you.

MR CHAPMAN (UCCO): I won't labour too many points, because everything is in the submission, which you have read and which will be available publicly anyway. But there's just a few points to which we want to draw attention. The first is to say that UCCO is incredibly supportive and excited about the potential behind this inquiry and the outcomes that can come from it, primarily because it's about providing that quality of life that we would expect for ourselves and expect for anybody else in the situation.

That's about two things, not just about the dollars. So clearly that there's a need to increase the amount of funding that's available to people to get the services and the physical needs that they need to have a good quality life. But it's also about overcoming the current inequalities that we face. We have already heard examples previously this morning about TAC funding versus no funding, so to speak, and those other inequalities, and this is hopefully an opportunity to overcome those inequalities rather than just moving those inequality barriers to somewhere else.

Briefly a little bit about UCCO, we are a not-for-profit provider of services to older people, people with disabilities and unpaid carers. We're community based, so the services that we manage are around people who are living at home, by and large. We have been operating for over 20 years in the eastern metropolitan region. Part of the broader Uniting Church network. The position that we're coming to this inquiry with, as we come with all of our work, is around that philosophy of a good life for all, which is our motto.

Within that commitment and it's the approach with which we're coming to this inquiry is around such things as a strengths based approach, so looking at what people are capable of rather than looking at what they're incapable of doing; being person-centred and person-directed, that it is about the individual; being innovative and flexible in supports, and we have heard a lot about that already and the difficulty when there isn't that flexibility, so ensuring that we can create new ideas, we can be innovative; and part of that also is being well-integrated with the community, to see what is available out there, what is a paid service, what is a voluntary service, how people can be included more in their local communities.

In regards to the disability support scheme, one of the first issues we wanted to raise is that it needs to be something that's rights based. The current system clearly does not adequately support an individual's rights when they have a disability, and as a consequence we see and have heard, as we have heard today, the stories about people having to constantly fight for the things they need rather it being provided to them as a human right. Part of that is having a scheme which is about being a basic entitlement, that safety net, for individuals who experience a disability, whether that's acquired, whether that's from birth, whether they're 55 and ageing already, and avoiding that issue that we have already heard this morning about who is worth spending money on and having to avoid that criteria.

It's also about ensuring that the dollars are adequate in that basis entitlement, that support is reasonable for a dignified life and that it does enhance the strengths of an individual, and also that the dollars are provided in a way which is able to be flexible and be expandable on what is required, that it can be about services, if that's what required, but it's also about such things as transport, such things as housing, such things as respite, recreation, that it isn't narrowly defined. Related to that, the other main issue that we come into the inquiry with is around that person-centred and person-directed support, both in terms of the funding itself and also in terms of the support planning, that the person with a disability is the best person to decide what they need and how it should be delivered; they're the experts, as we have seen today already.

They may need support in determining this. No-one would assume that you just throw people a bucket of money and say, "Well, off you go and deal with it, " but responsibility and authority needs to remain within the individual, and it's the responsibility of the government and of services such as ourselves to make sure that they are supported so that they can use that to achieve the best outcomes for themselves; that individuals are capable of finding solutions and approaches which professionals are not able to see. I think professionals bring a certain range of experiences and certain understanding to someone's disability, but clearly the person suffering that disability has a clearer understanding of a whole range of things on which we can never pretend to be experts.

Another issue is one around whole-of-life planning. The current system that we have is very narrowly focused, very crisis-orientated. We need to step back and take an approach which is focused much more on what is going to be the whole-of-life experience for this individual, from birth, in some cases, right through to schooling, to the transition to tertiary education, transition to work, relocation, that someone with a disability isn't necessarily going to live in one location for their entire life. Life transitions, how we're going to support this individual through marriage, through having children; and for retirement as well, an area that we see is constantly left out, that we assume that people with disabilities don't retire, they just die, and that's something we need to address.

Any support scheme has to also have community development as part of it that's working towards ensuring inclusion of people with disabilities in the broader community, but also increasing the options for those flexible, innovative community based supports and helping the community understand that any sort of insurance or support scheme is as much about them as is something like WorkCover or TAC. A lot of people see disability as something that's not going to relate to them. As we have seen the stories today, and I'm sure you have through your time, disability can be about anybody, and we don't question that with things like TAC and WorkCover.

The final issue which we have been dealing with a lot is around workforce development. That's a very critical issue, in the sense that additional funding and additional processes to improve the system are great, but if the people aren't actually there to do the work it's still going to reach a bottleneck. We have noticed that a lot in the ageing care sector, that there just aren't the people to do the work. There are three ways we need to approach that issue. One is about obviously increasing the workforce; that might be about improving the attractiveness of the sector, through whatever means, be it dollars, improving training, making work more flexible, who knows what.

But also about using innovation to decrease the demands on the workforce. So that might be about the use of technology. It could be about creative use of existing voluntary support in a more planned and cohesive way; you know, can we provide family members who are currently already doing that work with the funds to do that. Also, as we have heard previously, working far more around the early intervention side of it, applying those resources, doing that planning around early intervention, which will then reduce the amount of workforce that's required to supply their needs further down the track. They're the main points. I don't know if Scott or Angus want to add anything at that point.

MR SHEPPARD (UCCO): I think you've done it really well, Eddie. We're happy to answer any questions, hopefully.

MR KALISCH: John, do you want to kick off?

MR WALSH: Yes, thanks very much, Eddie. Can you hear me okay?

MR CHAPMAN (UCCO): Yes.

MR WALSH: I have a couple of questions. I'll start off with the workforce. We have heard a lot about the sort of people who can make the best or most appropriate support workers and a lot about the ability to, as you have described it, understand the needs of the person with the disability. How can you select the right people with those skills and/or help people to apply those skills? Do you have any examples or places we can look to to find where that has been done successfully?

MR SHEPPARD (UCCO): My experience and a lot of service provider experiences is that a person either has the capacity and an understanding to be a good support worker or not. So we tend to go on the person, on their values and their attitudes. Whether they have got a qualification or experience, in my view, is secondary. If they have got the right attitudes and capacity, then they can be taught and trained the specific skills to be able to do the work. We have found in the majority, as Shaunagh explained, it's about the person that can understand, can communicate, is respectful, then they can learn the techniques and the skills that are necessary to be in the direct support provision.

It's a bit of a contentious issue in the sector at the moment. There is a quarter that says that it must be more professional and have much more qualifications, higher pay and a more narrow band of what a person can and can't do. I know a lot of people with disabilities say, "You can't tell us who we can employ or not employ. It's much more important that it's the person that I like and can understand and can work with, whether they have a qualification, whether I pay on an award or not." So there is that dilemma, I think, around workforce because of course it should be the right of a person to be able to choose who works and supports them in a very personal way.

For those that can manage that themselves and make those decisions then I would say that's a good outcome. But for some people they can't and they need the protection, if you like, of making sure that the people are qualified, that there are the appropriate checks and balances in place so that the service provider, the funder and the service recipient can be both protected and safeguarded against as well. So I think that there is a dilemma there. I don't know if there is an answer to that. I think the answer is to provide a system that can make sure that the accountabilities and safeguards are in place but at the same time allow for personal choice as well. Do you guys want to add anything to that?

MR KERR (UCCO): I suppose in regards to direct care - and I suppose it's an assumption on my behalf - how valued is a being a direct care worker as a career? It's increasingly becoming casualised. So in terms of people with disabilities in having permanent ongoing carers with whom they can build some rapport and trust. We're often finding with the individuals we work with there's a constant flow of different carers, because, you know, it might be nursing students, it's a fill-in position until they get something that they actually want. So how do we actually make it a valued position, that people actually want to come into that as a career. It's quite a low-paid position, and that increased sort of casualisation of that workforce is becoming an issue for us when we're trying to support our people we work with to get regular and ongoing carers.

MR WALSH: You mention in your written submission targeted migration as one idea. Have you done any work on that or any investigations on that?

MR CHAPMAN (UCCO): We haven't done any specific work round migration. I think the reason that came up was that recently we have been working on I think the senate inquiry into persons with a disability and their ageing carers. That's one of the issues that has arisen there, is whether you could use skilled migration as actually a way of attracting more of our staff. It is happening I know from South Africa, a number of nursing people come from there, and so on.

The catch that we have found even in that sector, as Angus referred to, is they come in for a certain period of time and it's a fill-in before they move on to something that's better paid or something that they see as more of a future career development. So getting the people over here I think is not so much the issue, but actually keeping them working in the sector is probably the bigger issue that we need to deal with, and if we fix that issue then the migration might not be such a big issue in the first place.

MR WALSH: David, I'll just go on, on and then you can go ahead.

MR KALISCH: Yes.

MR WALSH: You say that you started with providing support in the aged care sector, and then into disabilities. Do you do any work with children with disabilities? I'm thinking about the early intervention opportunities and just wondering whether you have any experience with children with autism or other intellectual type disabilities and the value of intervention for those people?

MR KERR (UCCO): Yes, we're currently funded to provide flexible support packages which work with from the ages of zero to 65. Yes, we do have a considerable number of young people with autism to whom we provide case management services.

MR WALSH: Can you comment a bit on the opportunities for early intervention and getting better outcomes for those people?

MR KERR (UCCO): Yes, I think the thing we constantly find in those transitional points from zero to six, when kids enter primary school, the issues around going to mainstream schools versus special schools. So there's those transitional points. A key amount of our work is around those transitional periods with families, and those sort of early intervention strategies are really important. In terms of a lot of therapies and stuff that people are able to get funded for, often it's for kids over the age of six. So there's a big gap, we're actually finding, in those zero to six ages, in how we support them with those early interventions.

MR SHEPPARD (UCCO): If I could add that I have done a lot of work with older people with disabilities and it is a generational thing. Because they weren't given the opportunity, the early intervention and the skill development as children and as young adults, they aren't capable of living a more independent and productive life, and that's a real shame.

But our experience is if you can get the interventions in early, as children, then their skill development, their potential, can be reached. Just purely from an economic basis, in terms of spending government money, in the long run and in the long term of a person's life the investment is made early and the person then can contribute to society in general; but also their support costs are less in the longer term; and the families and their carers that work with them are then able to contribute longer term to society at a lesser cost as well. So that has certainly been our experience.

MR KERR (UCCO): Just with children under the age of six, for example, the flexible support packages at the moment are case management packages that have some brokerage attached, quite a small amount. But for those whose needs are beyond that, currently the stepping process we have is to apply through the disability support register. But we can only do that for children over the age of six at present. So children under the age of six are not eligible to have an individual support package through the department at the moment, so that's a big gap.

MR WALSH: Just extending that question a little bit, on this related question of what constitutes a severe or profound disability, do you have any view on what the open coverage of a new scheme should be?

MR SHEPPARD (UCCO): I certainly think it should cover the existing definitions of disability, be they sensory and physical or intellectual or acquired psychiatric, and certainly to include at birth and acquired through life's journey. I think there could be a distinction to be made at, say, 65 or where the aged care services eligibility kicks in. I think you could distinguish and say that a disability or impairment that's acquired due to ageing at that time can be catered for through aged care services and not necessarily disability but that a person would still have an entitlement for disability support because of their disability but also then to be eligible for ageing services as they age rather than be seen to be double-dipping, as they are currently.

MR WALSH: Thanks, David.

MR KALISCH: Thanks, John. Just picking up on John's question a little bit more. The challenge for any new scheme is actually moving from where we are today to where government might accept a scheme might be in the future. In that transition point is there any sense of where relative priorities might be first approached in any transition, from essentially a scheme that people say has too few resources and too much structure around it to one that is more innovative and more available? Are there particular groups within the population of people with disabilities that you see have particular needs that should be met as a first priority?

MR SHEPPARD (UCCO):   That would be really tough. I wouldn't want to in any forum offer a view on whose needs might be greater, and I don't think I would. To look at it clinically, if you like, say that there's only so much to do and you had to make a start somewhere, if you actually started at the earlier stage, with children and with young families as they're growing and, if you like, put in place a scheme that met their needs, then I think long-term, looking at a society's needs and population, then at least you'd know that that's building a foundation and building a population that will be supported; and it's just a pity for us older ones that are going to miss out, if you like. But that's all I could offer on that one.

MR KALISCH: You guys?

MR CHAPMAN (UCCO):   Like you, I'm hesitant to try and draw those boundaries around that. But I think Scott has got a good point. Where there is potential for early intervention, even if it's an older demographic, I think it's terribly important. I think also putting a certain amount of emphasis on, to put it simply, "Where do you apply more funding?" if that was going to be, "Who gets the money first?" But also about putting some very early work into I guess moving out the inequalities that might already be there.

We're aware that people with very similar levels of disability can often receive in a sense very different packages, and a lot of that comes down to the individual's advocacy skills or where they live regionally, as has been mentioned before. So it's about working on that consistency I think first and foremost, even before we start working on the funding amounts. These issues that were raised before about regional discrepancies, we think are appalling, that you can move from one location to another and suddenly your assistance has changed. But also in terms of that consistency across a life plan.

An example which was given to me this week was of someone who is currently receiving respite for a child who is I think approaching 16 or 18 and at that point they won't be eligible for respite any more. Nothing else has changed, it's not like that person is more capable or suddenly their parents can do more; one day they're going to get respite assistance, the next day they're not. I think smoothing out those inconsistencies and they inequalities, even before the funding kicks in - we don't want to put that off for too long - would be a respectable first step to make.

MR KALISCH: Thank you. You provided us with a bit of an indication of some of the learning you'd received from being a longstanding service provider and certainly a dimension around generational differences in terms of support and early intervention. What I was just going to indicate is that we'd really appreciate some information on that aspect and from your perspective where you've seen early intervention in newer generations actually make a difference.

You're one of the few large service providers that we have had appearing before us at this stage. I wanted to just get a sense of reaction from you as effectively an employer and a provider of services, whether you do see a challenge for yourselves as a service provider if there was a move towards more individualised service funding where people with disabilities actually had the choice to use your services, or, conversely, not use your services.

MR SHEPPARD (UCCO):   Yes, absolutely that's the situation in Victoria. We're actually going through those reforms, where we're moving from the old block-funded institutional-type service provision to through the state plan, where there is the rhetoric of personalised services and individualised funding but the actual service system hasn't caught up yet. So we're actually playing that out. We certainly believe that as a sector there are challenges for service providers in that, but inherently it is the right thing to do.

So it's up to service providers to respond and evolve accordingly, and I think a market-driven, if you like, system would be a good thing, because a person should be able to say, "I'm not happy with the service I'm getting now, and I'll go to service B and get a better service." So I think there will be a degree of rationalisation and shakedown in the sector. I don't think that's a bad thing. But I think it needs to be done very carefully, in light of the current community sector providers who are not-for-profit and who have been created primarily by families of people with disabilities and people with disabilities themselves over the last 50 to 100 years, where there were no services, so they actually built the services and the organisations up.

Most service providers in Victoria have that mandate in their constitution, whereas in an open market where for-profits could actually come in and deliver services and perhaps not have that same mission and goal that community service organisations have I think they'd have to be very closely monitored and looked at so that it couldn't be cherry-picked. I think there's some examples in other sectors where for-profits have come in, like in childcare, to the detriment of service recipients and to the sector.

MR KALISCH: Do you think in that evolving environment, if it was to move towards more of a sort of individualised based funding where consumers essentially had the choice of who they received services from, that we'd see new service providers also emerge in the not-for-profit sector?

MR SHEPPARD (UCCO):   Yes, I think that's what we have seen now and I think a lot of organisations have changed the way that they work and they're responding to that. But I think we're testament to the fact that it does work. We have reshaped our systems and our ways of working so that we are directed by the person within the constraints of the current system, and if that current system can be adapted and changed then the choices and the outcomes for the individual are going to be even better.

MR KALISCH: So do you receive regular feedback from those that fund you?

MR SHEPPARD (UCCO):   Yes, absolutely. That's fundamental.

MR KALISCH: How does that affect your operation?

MR SHEPPARD (UCCO):   That can be difficult, because sometimes you don't like to hear the shortcomings of other providers or staff. But as long as it's done respectfully then that's a good thing. Also, there's some things that people aren't happy about, but, you know, it's mandated by current policy and restrictions that are in place, so sometimes you are in a hard position. I think there needs to be independent review and a quality framework in there, but any quality framework has to have a personal outcome measure in it. So it's no good measuring the service by seeing what the policies and the procedures are in, through an audit; there are good reliable measures where you can actually talk to the person who receives the service and let them determine whether the outcome is there or not, and I think that would be the best measure of any quality system and of a service provider.

MR KALISCH: John, is there anything else from you?

MR WALSH: Yes, just one more, David. On this issue of service provision management and the tension between funding and individual funding. You guys would be aware of the recent discussions around national awards and the fair awards in the sector. At first reading those awards appear to make it more difficult to have a flexible and casual arrangement with individual funding and move more towards more rostered type arrangements. Do you have a comment to make on that, and is there anything that needs to be considered in those discussions?

MR SHEPPARD (UCCO):   Yes. A new federal award where community service organisations aren't discriminated against should happen. So they should receive parity in terms of their wage remuneration. If we don't' do that, if we don't properly remunerate the support workers or people who work in the filed, then we're always going to have issues around the quality and the calibre of people who work there. But in terms of some of the other restrictions in terms of awards, like minimum hours of shifts and things like that, I think we have to shake up those awards and have some more flexibility in there.

In safeguarding the rights of the employee, we have circumstances where organisations will go in and do a one-hour shift here and a one-hour shift there, which is fine, but they have actually employed the person for the eight hours, and so they're working very flexibly and individually with people but they have got the security and the continuity of a full five or six hours of employment for that day. So that actually works. But I think we have to tackle full-on the issue of whether a person with their own package can employ a partner, a cousin or a neighbour to do some sort of direct care, or any type of support that they want.

That's an issue that needs to be resolved and there's probably a thousand reasons not to do it, in terms of IR risk-minimisation and things like that, but, fundamentally, it's a natural human intercourse and relationship that can occur that way, so I think it should be allowed to happen. I think you can put some safeguards and some accountabilities around it, but we need to deal with that and create a system that allows that to happen and not let IR legislation block that. I don't know how you do it, but it's an issue that needs to be addressed.

MR WALSH: Yes.

MR KALISCH: Any more questions, John?

MR WALSH: No, thanks, David.

MR KALISCH: Thanks, guys, and thank you for the opportunity to come here. We're going to have a short lunch break and then resume again at 1.30. Thank you.

(Luncheon adjournment)

MS SCOTT: Good afternoon. We might recommence our inquiry's public hearings, and I call to the table George Vassiliou. George, when you're ready, if you could just identify yourself. Are you representing an organisation?

MR VASSILIOU: I'm representing a group that was established to support my daughter but I also have a very fluid sort of association with a group called Friends of EACH in the aged care area. We made a representation to Better Care to the previous commission - or there was a report that was commissioned by the family and community services minister.

MS SCOTT: Yes, okay.

MR VASSILIOU: My name is George Vassiliou. I come here as a carer of a person with a disability and also of a person in the aged care area. I've been involved in the disability area for probably 28 years and more recently in the aged care sector since my mother became I suppose a candidate for support. She wanted to live in her own home and I provided quite a substantial amount of support to get a program under way to support her to remain in her own home.

I've always promoted a grassroots approach to the provision of care. I think there's an attitude that's developed that I call the professionalisation of the aged care sector and also disability, where you have a whole lot of attitudes developing that maintains that there is a difference between formal care and informal care, when in fact most people with disabilities and aged people are at home either on their own or with the care and support of a family member. That sort of care is deemed to be informal support, whereas paid support by the professional sector is deemed to be formal support. I just want to highlight that because it seems to imply that informal support has less credibility or is less valued because it's not paid for.

The idea that I have is to promote individuals to fundamentally look after themselves because we need to keep people active and in the community for as long as possible, and I'd like to cite some figures from the Productivity Commission itself that talked about the aged care sector not long ago, where a person in an aged care facility would cost the system between 150 and 200 thousand dollars a year. The current model that we have - and it's a pyramid drawn on your issues paper - talks about the current system, how it's structured. It's on page 7. I think we've omitted in that model to understand the impact and the importance of what's referred to as informal care.

If we look at the apex of that pyramid, I think that the higher up we go, the costlier the service provision is in the system and the least costly is people living either on their own or with the support of a family member, and yet that is the most undervalued and underfunded area. I think lately the minister, Justine Elliot, has seen the light, I suppose, and the government recently, to add another $247 million for packages that allow people to remain in their own homes for as long as possible. They are the EACH packages, CATS packages, EACH Dementia, and so I think that's a great move forward.

Fundamentally, I think we have in our community models or approaches that recognise the importance of valuing our elderly citizens. However, the application of that I think leaves a lot to be desired because we have a lot of waste with the current system. When I first entered the aged care sector, searching for solutions to allow my mother to remain at home, I was confronted by a lot of negativity. People proposing ideas from the grassroots were not very well accepted. If I was a professional, if I was a person representing an organisation, I think I would have had a better time. However, I struggled in my approach to be heard and to propose. It's very difficult to propose, and I have to say things have changed somewhat in the last couple of years.

The experience of family care members has been I think horrendous and it continues to be horrendous for those who dare challenge the system. People are basically told to apply, to wait, be assessed, wait and continue to wait. I think we have a lot of people waiting and I think a lot of people either die waiting or family members get exhausted by the time they get actual support.

What I said to the system when I approached it was, "I don't want any more money, I want to control that bucket of money," which was called EACH Dementia, the extent of the home care packages. I was told it was $48,000. That's the value of the package when it leaves the federal government budget area. However, by the time it reached my mother through this organisation, I was lucky to get 10 hours a week. The operational costs of the organisation - I'm talking a few years ago - at $30 an hour, that's $300 a week. Now, if we make the maths simple, 30 times 50 weeks, that's $15,000. I did my kitchen maths, started off with 48, take away 15, there was $33,000 that could not be explained. I asked for explanations from the organisation and their response is, "Well, you know, George, we have administration costs, we have case management costs, we have ancillary costs." I said, "How can you justify $33,000 going into the ether?" There was no explanation. I was pushed, I was redirected, I was asked to do certain things. In fact my mother was assessed by the organisation to prove that my mother needed to be institutionalised. That was an affront to me and my family. The fact that my mother wanted to remain in her home, the family wanted my mother to remain in her home was totally discounted.

The system doesn't look at the qualitative aspects. What we talk about is events, we talk about hours, and there is no awareness of what and how those dollars are spent. What do we get for those dollars that we expend? Unfortunately the organisation that supposedly was out there to support my family and my mother, my mother in particular, was more interested in retaining the $33,000 as part of their administration, case management and ancillary cost component. Now, I was lucky enough to pursue this because of my previous experience in disability. The model of consumer-directed care is not new in Australia. We have this cringe mentality. We have to go overseas, bring all these professionals to tell us what we already have been doing. The idea that I got on to had already been operating in Australia. It had been operating in the disability sector, operating in the aged care sector. The only difference is that I went public, and for doing that, there was a bit of recrimination and negativity. I pursued. We got to the point where I had a meeting with Justine Elliot, and in fact there was quite a lot of media attention through the little group that I mentioned, Friends of EACH. We got quite a bit of media attention. In fact there was something on The 7.30 Report, Radio National and Senior magazine.

The sad part about all of this is that here is something that is creative; the organisation that actually hosted or sponsored my consumer-directed model of care did not pursue this. In fact they were I think pressured by relevant authorities or bodies to do a pilot. You know, hello, we've got a model that's working. I didn't run away with the money, I didn't abuse and deal negatively with my mother. My mother was quite safe. There's all this thing about elder abuse. The system, the model that we had, was operating very effectively. I was able to get from 10 hours under the proposal by the previous organisation to 30 hours a week. Now, that is an incredible improvement in the bang for the dollar, so to speak.

I recall having a conversation with a federal parliamentarian about my proposal, and his response was, "George, I'm not prepared to denude the service system." I said, "What do you mean by that?" He said, "Well, you know, we're talking about employment here." I said, "If I can get from 10 hours to 30 hours, I think I'm creating employment, and remember I didn't ask for any more money. I'm able to do a lot more with the same bucket of money." What I was trying to highlight also is the fact that we have the Australian ethos of people doing things for themselves, and what we're developing over the last generation is we have people who are being told to be quiet, to wait and to be dependent.

We have this attitude of dependency, this creation of dependency in our community. It is wrong, it is ineffective, inefficient and it is life-wasting, dollar-wasting and time-wasting. We cannot buy time. Time cannot be bought, because people spend a lot of time agonising about what is going to happen. More and more of the burden of responsibility is being pushed back to the family caregivers or the individuals themselves. We have this greater share of the allocated budget to case management, administration and ancillary costs.

This is I think a scandal the situation that exists. We have this corporatisation of the care service system. We have bigger and better offices, carpeted offices, and I remember saying to one of these bureaucrats and organisation people, at the way they talked to me, I said to them, "From the tone of your voice you've had a lot of airconditioning and ducted heating in your life." Clearly they're not out there in the real world at the coalface to understand how families are faring in this system. I have approached Justine Elliot to push this model. She has I think of late announced some 1000 packages in the aged care sector for respite and I think some direct care approaches.

But, unfortunately, we haven't learnt from the grass roots approach. My initial request from Justine Elliot was, "We need to educate people. We need to inform people about how this thing can operate." What we have in fact is a system that is top down again, things that people don't have ownership of, they don't develop these ideas, they don't take ownership. If something is delivered to you it is another model. We have had many, many models in our lives, and in fact I have been around, especially in the area of disability, for over 28 years, and all we have is consultations, models, bureaucrats proposing different things.

The bureaucrats are allowed to make proposals and take risks and make decisions, yet individuals and families are told to wait. You either fit the menu or you don't. If you dot' fit the menu, then you're on your own, okay. Remember, and I want to reiterate this, more than 93 per cent of people with disabilities are at home with their caregiver and certainly there's a large proportion of the aged care population that is cared for by a family member, a significant proportion of the population, yet most of the dollars go to the institutional sector.

In here there's a tension between the bureaucrats. Leave aside the minister, the minister I think is tied down by the complexity of the system. I don't have pity for her, but I fear that she is not in control of the whole system. The bureaucracy runs the whole system. We don't have a system of total accountability and responsibility, because if the act allows this model of care, that I was able to force through, why isn't it made public by the bureaucracy? Why didn't they take an initiative to publicise this as an option?

What we have is this collusion I think between the bureaucracy, their satellites, which I refer to as the providers, and the peak bodies. Recently there was a peak body report or a statement about this option of consumer-directed models of care. This model of care was operating at the time of the writing of that report, and there was only a reference to a family in Victoria that has actually undertaken this particular model of support in their elderly mother. They didn't even contact that family. They didn't even include any feedback or input from that family. That's the level we have with peak bodies. I think we need a little bit more openness and sincerity about the way they approach.

Let me say that the current system is not working, it is not effective and it is not efficient. If we take the dollar ratio, nearly 80 per cent of the dollars that are allocated go to case management, administration and ancillary costs of the organisation, then we have got a major problem. We cannot continue to grow the infrastructure and the bureaucracies to service this particular way of dealing with things. We need to move those dollars to where they have greater impact. There's many, many people that want to do exactly what I was able to do for my mother.

In fact, since the reports went out in 2008 and 2009, I still get emails from people who want to know how I was able to achieve this model of care for my mother. People have been sending me emails, letters and so forth. They have been able to track me down in one way or another. Unfortunately, as an individual, I am not funded. I do a lot of this work pro bono. Today I have taken time off to come here to speak to the commission because I'm passionate about what should be happening in this community. We have a great approach to dealing with our vulnerable people.

Don't get me wrong; the act in its approach recognises the needs of individuals and carers. The Disability Act in Victoria, unfortunately, doesn't even want to recognise carers. But the federal act, the Aged Care Act 1997, the one to which I'll refer, makes reference to the needs of carers. We need to involve in a meaningful way those people at the bottom of that pyramid that I referred to earlier. We don't have that inclusiveness. We have what we think are advocate bodies. There are no advocate bodies that are out there, to promote with a passion, that challenge the current system.

We have, as I referred to earlier, satellites that respond to the bureaucracy. If you do what the bureaucrats want you to do, then you are their top boy or their top girl. I can tell you, when I had the breakthrough, particularly in disability, the bureaucrats wanted to know exactly how they could learn from this. Once they colonised the idea, repackaged it and called it their own, the family was no longer to be involved. We have this fear of families. We have no independent advocacy approaches to assist families to gain information in Australia.

Many people have said to me that Carers Australia or Carers Victoria or Carers New South Wales is the advocate body. We have a situation here where an organisation that is funded by the federal government is not likely to be critical of or challenge or even be assertive in terms of what it actually sees. I say that with good cause, because this model of care of which I have sent you details I proposed to Carers Victoria in 2005. We are in 2010. Clearly there must have been some learning along the way. The organisation that hosted my program for my mother back in 2007 decided to do a pilot study. We don't have this zeal or initiative to get out there. Once a model works, then it's a work in progress, we develop that, we don't need to do studies. This particular organisation that hosted the arrangement that I had is doing a three-year pilot, and after three years they will determine whether the program is worthy to be rolled out.

MS SCOTT: George, would you welcome questions?

MR VASSILIOU: Look, I can talk, if you like.

MS SCOTT: No, that's all right. David, I think, has got a question.

MR KALISCH: George, you've obviously provided us with a very comprehensive discussion and a very forceful commentary around individualised packaging and consumer-directed care. That has been very useful and we have certainly got that aspect and certainly that's what you've been talking about. I was just wondering, in terms of your broader experience with both the disability and aged care services, whether there are other difficulties or other aspects that you think also need reform.

MR VASSILIOU: At the moment, David, the system is out of balance, because we have a lot of dollars and support for, as I referred to, the corporates or the providers; the families and individuals are really at the bottom end of that pecking order. We don't have adequate advocacy support. We don't have independent advocates. I can't go to a place to get information about the current system. People are saying to me, "How do I do this?" "Where do I get this information?" "Who can help me?" I can't refer them to anyone. I have sent out some literature that I've composed myself to people, but people are there on their own. Who will stand with these people? There isn't anything like that. We have an imbalance in the whole system. It is so lopsided that people are either exhausted or they give up and say, "Well just give me what you've got and I'll do the rest."

MR KALISCH: In terms of once people do age and become, partly, recipients in the aged care sector, do you have any sense of what should be provided in terms of the services and facilities through the aged care network, as opposed to should disability services also keep providing for people or should that responsibility transition across to the aged care sector?

MR VASSILIOU: Your own issues paper talks about a holistic approach and I think we need to be realistic about where people are at points in their lives. If you're a person with a disability, once you reach 65 you then become an aged person, you're no longer a disabled person, you're an aged person. I think we need to take a more sensible approach to negotiate and discuss these matters with the families, the individuals, keeping in mind that the basis support, or the backbone of the support, is the family and the family caregivers. We have omitted that. I mean, I have had so many people say to me, "Families can't be trusted," families this and families that; I think for a small portion of the population may be abusive of their people, may do things that are not right, but we don't punish the whole community because of those.

I had the same responses in the disability area, you know, "Families can't be trusted. The money may be spent at the casino," or the money will this and the money will that. Well, here we are 10 years down the track, we're running a fantastic program, Department of Human Services is now promoting consumer-directed models of care as a way, because this is the way to go. We can't find the resources. We need to get more value for our dollars.

If I can say again about value for dollar, what I discovered in my travels through this system was that, although the act doesn't say openly consumer-directed models of care can't be done, the bureaucrats, the providers, would say, "Your model is not permitted by the system, by the legislation." That is not correct. I think some statement has to be made about either the act making this explicit or a comment or some statement by the commission, for example, to highlight the fact that there is nothing in legislation that stops these models of care operating in Australia as they exist now.

MR KALISCH: Can I just get some clarification? Is the act you're talking about one of the disability acts?

MR VASSILIOU: The Aged Care Act. The Aged Care Act basically, as I understand, allocates the funds to the organisation, and, as far as the next step goes, the only time the department gets involved with the organisation is when they acquit for those dollars. How the agency, the provider, interacts with the individual is really up to the individual and the provider. That's fact. That's in the area of home community care. I have had that stated to me. But it's not explicit, people don't know that. If I say that, it has no standing.

MR KALISCH: Thank you.

MR VASSILIOU: The other matter with relationship to funds is - and I think this is very disturbing, commissioners, if I can say this - a concept that I discovered was the residual. Organisations are allowed to maintain the residual. That's code for "profit", and this is something that needs to be thoroughly investigated, because the reason why we have high costs, outsourcing of responsibilities, is to maintain as much of those dollars within the organisation.

The other complexity that arises is a lot of these organisations are church based organisations, and I think there's something in the constitution that speaks of churches receiving funding directly from government. I think we need to really investigate this, because I'm fearful that a lot of families and individuals are missing out on those dollars, because there is this usage of this residual by organisations to supposedly improve services. But frankly I have not seen much improvement in the time that I've been involved either in aged care or in disability of improvement in services. People are continually coming and saying to me, "We are not getting enough hours." How this happens, I don't know.

MS SCOTT: Can I just check one thing, George? You said that one of the problems that you've seen in the system is that when the government provides funding to organisations - these are not your words, but I've heard them used elsewhere, including here - those organisations can become captives - you referred to the good boys and the good girls, sort of thing - how then would an advocacy service funded by the government not fall captive to the same behaviour that you think you can see in the existing system?

MR VASSILIOU: There are independent authorities or independent bodies that can be set up whose funding is guaranteed, regardless of who is in power and who is the secretary, who is the state director of that particular agency that it's funding. I think we need a secure source of funding to keep and maintain that balance in the system. At the moment we don't have that. We have, on paper, advocacy. But I approached agencies, I approached the federal bodies, to assist me; and their response is, "We can't help you until your mother is actually running a program." I said, "In order for me to get this program under way I need your help." "Sorry, we can't help." Carers Victoria could not help. There is no-one else that would take this approach to support the individual at the moment.

MS SCOTT: Sorry to interrupt, but we're just running out of time. Is there any organisation that has an advocacy role, maybe in a different setting altogether, that you have confidence in, that you think we should use as a role model?

MR VASSILIOU: I don't want to denigrate any organisation, in terms of how they see themselves as advocate bodies. What I'm saying is the feedback I'm getting from people is that there isn't anything of value for them from these agencies.

MS SCOTT: Okay, so there's nothing you can think of.

MR VASSILIOU: I just want to maybe just reinforce that by saying that I challenged the secretary of the families and services ministry, Bill Shorten, about this advocacy. I told him there was no advocacy support for people in the disability area. His report to me was, "Yes, there is, George. We know there is." I said, "Well, you send me the names of these agencies," and he sent me a list of 20. My spiel was basically this, "I'm a carer of a young woman, she's 28. Whenever I go to speak to DHS they don't listen to me as a parent. I need you to be with me so that I can advocate for my daughter effectively."

Of those 20 organisations I located 12 that were metropolitan, because I knew that I couldn't go outside of Melbourne. I rang each one of those and 11 out of the 12 said to me, "We only support the person with the disability." I said, "Well, my daughter is quite disabled, she can't pick up the phone. If she could do that, I wouldn't be here." But that wouldn't sway them. They're funded to support the person with the disability. Only one organisation said, "We may be able to help. Leave your number and we'll call you back." They rang me back with a 1800 number, I rang that number and it was disconnected.

So I rang Bill Shorten's office and said, "Look, this is the situation. There is nothing in Victoria." His response was, "Maybe we misunderstood each other. There is no family advocacy" - he recognised that - "like the model in New South Wales," and he referred me organisations in Melbourne called VALID and STAR. Well, VALID, as we know, is an organisation that promotes - and they do a very good job - directly supporting people with disabilities, STAR is an organisation that has been de-funded so much and they're so under-resourced they could not help me. So effectively there is nothing. Getting back to the need for advocacy, I cannot stress that enough. We need those dollars to get out so people can have their voices heard.

MS SCOTT: George, I'm just conscious that we have now extended - - -

MR VASSILIOU: Yes. I have a lot more, but I understand that.

MS SCOTT: Thank you very much for coming today and for your paper to us earlier.

MR VASSILIOU: Thank you for your time, commissioners.

MR KALISCH: Thank you.

MS SCOTT: I call to the table Dr Joseph Toscano. Joseph, for the transcript, could you give your name and indicate if you're representing yourself or an organisation.

DR TOSCANO: Joseph Toscano. I'm representing myself, or actually the people I work for basically. They're a huge number of individuals, not an organisation. First of all, good afternoon to the three commissioners. It's good to see a few citizens here to keep the commissioners honest. That's the whole purpose of a public inquiry. I'll just give you two or three minutes' background on myself; what I do, what my ideas are, and then we'll open that up to questions. I believe one way to actually extend the commission is to get them to think about things and get them to ask questions about a field in which they may have no experience.

My name is Joseph Toscano. I graduated Bachelor of Medicine and Bachelor of Science at Queensland University in 1975, did my internship in Brisbane in 1976, came to Melbourne in 1977, worked in a Victorian spinal injuries unit between 1977 and 1982, and then in 1982 I began a part-time private medical practice looking after people with severe physical disabilities, quadriplegics and paraplegics. I did my Doctor of Medicine into the causes and aetiology of traumatic spinal cord paralysis, and I got that doctorate in 1987. I have spent 60 hours a week for the last 28 years looking after people with physical disabilities, profound physical disabilities and secondary trauma.

Obviously when we talk about disability we look at people who are born with a disability. They acquire one through a traumatic episode in their lives, like a road traffic accident, a simple fall at home or a workplace injury. It's either an organic disability, you're unlucky enough to get a virus or an infection or a cardiac problem or something and you find that your whole life is turned upside down in a matter of days, or, as you get older obviously there's all the frailties associate with old age. But what I know about is basically physical disabilities.

I learnt a long time ago that it doesn't matter how much effort the individual puts in, very little happens unless there's major political action and legislative changes, which affects tens of thousands, or hundreds of thousands of people. Because I have a home-visiting medical practice, I go into people's homes. I've gone into some of these people's homes for almost 30 years, so I have an understanding of what the issues are to them. The greatest thing that ever happened I think to people with disabilities in this country was the introduction of the attendant care scheme in the late 80s, because it opened avenues to people that it would never have.

They could actually stay at home with their families and friends, their lovers, their mothers, whatever, they could stay at home. It didn't happen before that; it was a real issue. But my concern is, as the previous speaker intimated, that 30 to 40 per cent of every taxpayer dollar that's allocated to these schemes disappears in administration costs, just disappears. My other concern is the difference between the quality of the service you receive as a person with a profound disability is dependent on how you get that disability.

If you're unlucky enough to be struck down by an organic illness, like a virus or multiple sclerosis or whatever, you get the Disability Support Pension if you can't work plus what you can get out of the attendant care scheme. If you fall off your roof at home and there's nobody you can sue for negligence - and 60 per cent of people with severe traumatic spinal core paralysis, I'm talking about quadriplegics - have no compensation. But if you're involved in a road traffic accident or a WorkCover injury, depending on the different programs in the different states, you get a much better level of care, and that level of care gives you individual and personal options. Care equals options; no care, no options.

The difference I see when I go into people's homes is not just the quality of the life they live if they got compensation, it's the options they can access. Somebody in a package gets 36 hours a week; somebody under TAC or WorkCover, with the same level of disability, can get 24-hour care. A huge difference. Disability the same, the cause different. So to me it's a political issue and it rests with two things. One, I think we need a national compensation scheme which is funded through a levy, like the Medicare levy, which is actually put on company tax as well as individual tax.

How big that levy is is dependent on how many groups you want to bring under that umbrella. Is it just going to be trauma-related, for people who don't receive compensation? Do you get rid of the WorkCover and TAC and actually have a national compensation scheme? Do you bring in people who are born with disability, to assist them as they grow up, and their families, financially as well as physically? Do you bring in people with organic causes? Do you bring in problems with frailty and old age?

Obviously the more people you bring into the scheme the bigger the cost to the whole community. I think there is a mood for a national compensation scheme, because I think people are beginning to understand the cost of care, the fact that we're all human, you know, "but for the grace of God". Tonight one of us could have a stroke, be hit by a car on the way home, it could happen to anybody. I think the fact that it can happen to anybody - and it's not a sectional interest, if there's the political will, you could go ahead with that.

I don't want to bore you with any more. As I said, I believe we need political changes. I have spent 34 of my 35 years as a doctor working with people with physical disabilities, 28 of that in the private sector. I spend a minimum of 60 hours a week 50 weeks a year working. I really have made no change, no difference. The biggest change was the introduction of attendant care, end of story, a political decision.

MS SCOTT: Thank you very much, Joseph. You have articulated a lot of questions. In your submission to us you recommend that the scheme that you're supporting, a national insurance scheme - paid for by, say, a Medicare levy - be administered by regional councils. I just wanted to ask you a few questions about that, if I may.

DR TOSCANO: Yes.

MS SCOTT: By regional councils, I take it you don't mean local councils, as we have now. Or do you?

DR TOSCANO: No. I'm very interested in the new health care set-up, with the councils that are going to be set up. I believe the state outsourcing its responsibilities to the private sector has been a mistake, because most of the money gets lost. I believe it's inefficient. I believe they don't provide the services. I think that it should actually be administered by the state, either through the community health services network or through the larger public hospitals, they have a special division which actually does the hiring and the training. It's a whole new level of government. It's against the current trends for government to divest themselves of responsibility. What they do is they put out a package, some money, and then they say to the private sector, "You contract for that," and there are huge amounts being lost.

MS SCOTT: The regional council model to which you're referring, I take it that's part of that COAG reform process.

DR TOSCANO: Yes.

MS SCOTT: So we don't actually have a working model that we can look at in existence.

DR TOSCANO: In the interim, if that doesn't come through, you could actually look at community health centres, you could look at the regional hospitals.

MS SCOTT: Okay.

DR TOSCANO: It's a new department. I know it's a new bureaucracy. But my belief is that bureaucracy actually costs less than the money that haemorrhages out of the private sector.

MS SCOTT: Thank you.

MR KALISCH: Just one question about that, Joseph, and I understand the dimension you're trying to get at, in terms of utilising organisations in bureaucracy, that it's going to be there for another purpose anyway, in terms of these local hospital networks that the government is talking about. Do you think, given that those local hospital networks also have the responsibility to fund public hospitals which can soak up as many dollars as they get, that there might actually be a risk of diverting funds that might otherwise be used for people with disabilities into acute care services?

DR TOSCANO: That's why we have auditors.

MS SCOTT: All right.

MR KALISCH: So to have boundaries.

DR TOSCANO: What you do is you say that they put in a submission, "There are so many people in our area that we're responsible for," they put in a submission, they get so much back; and it's quarantined, and if it's not used it goes back into the general funds, into treasury.

MS SCOTT: John, do you have some questions for Joseph?

MR WALSH: Yes, I do. Joe, I don't know if you remember, we did some work together 20-odd years ago when you were - - -

DR TOSCANO: Did we? I thought your face looked familiar when I saw it on the screen. I said, "Who's that old bloke I know?"

MR WALSH: At that stage you were looking at the potential benefits of early intervention and very early management triage.

DR TOSCANO: Yes.

MR WALSH: Is that something you've pursued and is there any opportunity for effectively prevention of the escalation of the effects of trauma through better early management?

DR TOSCANO: I think there is, and I would see maybe an overriding federal body, if there is a national compensation scheme, that some of the money that comes in would actually be directed at federal - not state based, but federal - schemes to actually try to reduce trauma. Simple things like people falling off roofs, when they're cleaning their roofs. So devolve the responsibility, you'd actually centralise the responsibility from the states to a federal body. If there is a national compensation scheme, such a federal body would actually have the ear of all Australians.

MR WALSH: My other comment is with this idea of a regional council I think you're implying that that might be a fund-holder. How does that link in with evidence we have heard from other people that the model is a consumer-directed model? So how do you link the medical care and the medical intervention with people's own choices and life goals?

DR TOSCANO: You have options I think. You give people options. You can have self-funding, like TAC does; although they have actually stopped that program in Victoria. My experience is that only a small percentage of people, those who are more articulate, tend to take it up. Most people don't want the hassle of running a program, what they want is to get bang for their buck. So I think there should be options. You can offer a self-funding model. You can offer a model where the regional centre actually runs it for you. I do agree there should be that option.

MS SCOTT: I have got a few follow-up questions, John. Is it all right if I interrupt your flow of thought?

MR WALSH: Yes, of course.

MS SCOTT: You said that you didn't think many people were taking up the individualised, "I'll control my own package." Is that because of lack of confidence or skills, or is that because it's not advertised enough? I have had someone put to me today that the reason why people weren't taking up being in control of their package is simply because they weren't being given the option and they weren't aware of the option.

DR TOSCANO: What takes you and me five minutes - like we get up, have a shower, go to the toilet - can take a person with a disability two hours. The key is time. If you run your own package you do have control but it is time-consuming, and some people don't want that hassle. They have got enough hassles in their life - with their personal relationships, trying to get some work, all the medical issues they have got to deal with - and they'd just like to have an efficient service, where they get the maximum return for the taxpayer's investment.

MS SCOTT: John, back to you.

MR WALSH: I don't have any more specific questions, Patricia, thanks.

MS SCOTT: Joseph, I think you could help our study, if it's possible. We wouldn't want to know the names of the individuals, but you know how you gave the example of someone who would be eligible under the TAC for 24/7 care versus 36 hours a week if they weren't in the TAC scheme?

DR TOSCANO: Yes.

MS SCOTT: This is a tall order, but I guess I'm interested in someone who has the same level of functionality but has acquired the disability in different means, and we would be able to de-identify it as a case study for just how different the level of support can be. We have written about it in our issues paper, but it's another thing to actually be able to quote reality.

DR TOSCANO: Obviously I've got to ask patients and get their permission.

MS SCOTT: Yes.

DR TOSCANO: But I'm sure there would be people who would be more than happy. In my practice it is a constant talking point, the different level of care depending on the type of accident you have. It is a huge talking point. It causes division. It causes a lot of anger. People say, "Well, I fell off a roof and 30 years later I'm in a ministry house and I'm trying to survive; and Jack down the road he was hit in the car and he's getting his wage, $450 a week, and he's getting 24-hour care. I'm going to have to go to a nursing home, because my wife is old, and he can stay at home" - or, she can stay at home, because they have got 24-hour care. I'm quite happy to do that. I can find some articulate people to do that. What is the time frame? That's my dilemma.

MS SCOTT: We have till February next year to write a draft report.

DR TOSCANO: Plenty of time. All right. How many do you want? Do you want four, 10, 15, 20? How many people do you want? Tell me.

DR TOSCANO: So you want people to come in and talk - - -

MS SCOTT: No, no. I guess what I'm looking for is person A and person B, the medical diagnoses might be very similar - I guess the more similar it is the better.

DR TOSCANO: So you want me to do the work?

MS SCOTT: Yes, that's right. I did ask you.

DR TOSCANO: I've worked it out now.

MS SCOTT: The functional capabilities might be pretty similar.

DR TOSCANO: I'm happy to do that and I'm happy to provide their names and addresses and phone numbers, with their agreement.

MS SCOTT: No, we'd actually be happier if it was de-identified.

DR TOSCANO: I'm happy to do that. But then you'd have to trust me.

MR KALISCH: We'd be looking for a paragraph or two, we're not looking for - - -

DR TOSCANO: I'm happy to do it. Maybe I'll tape some people.

MR KALISCH: Just so that we can actually get some - - -

DR TOSCANO: What I may do is I may tape some people and get it transcribed, because I'd like for it to come out of their mouths.

MS SCOTT: Yes, that would be great. All right.

MR WALSH: Actually I do have another question. Joe, your practice, as far as I know, is a unique practice.

DR TOSCANO: That's right.

MR WALSH: It seems to me that there are a lot of potential positives in having someone like you, who is an expert in your area, servicing a very wide clientele. People in Victoria are getting the expertise of a spinal specialist on-call effectively, which I don't think exists anywhere else. Do you want to comment on that?

DR TOSCANO: I'm not a spinal specialist, I'm a humble GP with a special interest in spinal cord injury. It has been my lifelong special interest. I'm thinking of retiring in three or four years' time, and I can't even give away my practice. I do it because (1) I'm interested in the work, and (2) I find it rewarding, and it suits my lifestyle to be able to control my practice. You can do it, and some of the hospitals are doing it now with nurses, they're trying to send out nurses to do this type of work, and they have got packages from the Commonwealth government to do it.

But I think you would maybe have to have some type of career structure in place and pay them a more adequately than I get paid. I bulk bill, because obviously my patients can't pay, or I bill TAC or WorkCover. So you really need a structure to entice younger people to do this type of work - and it is very rewarding work - and maybe have a career structure and a pay structure, and they could actually be attached to this regional model.

MR WALSH: In terms of the economic benefits of your practice - and I'm guessing, and I'm asking you to fill me in here - you would be providing a lot of benefits, in terms of helping people with pressure sore management, urinary tract infection management, that would effectively keep them out of hospital.

DR TOSCANO: Yes. My motto is, catch the problem early. Somebody can ring me and I can see them maybe within a week or a few days and have a look at a very early pressure area, have them up and moving in two weeks. There are people who spend three or four years in hospital and then the rest of their life in a nursing home because they have let a pressure area go because the local doctor doesn't understand what they're dealing with, or the RDNS, or whoever, don't understand what the issue is; although things have improved, I must admit, in the last decade they have improved.

With wound clinics and pressure clinics there's a much greater awareness. But there is a huge cost, because spinal patients and people who have had injuries are very, very expensive to the community. We're talking about millions of dollars on one individual. You think of the cost of keeping an individual in hospital, with all the surgery, for three to four years; and it happens, just go to the Austin and ask them. So it does make a difference to pick it up early, a huge difference.

MR KALISCH: Joe, you talked about the nature and potential breadth of the scheme. One of the aspects that certainly we're thinking about is whether you do actually have a national scheme or whether you have national arrangements that complement other services such as TAC or long-term care in New South Wales, whether you keep those systems in place that are operating or whether you fold them into a national system. Do you have a view on that?

DR TOSCANO: I'd like to see one national system. But initially, obviously, there are people who will want to keep their TAC and WorkCover arrangements, which are different in each state, some are better than others. It may be an intertransitional network where over a period of time those schemes are phased out. I don't believe these are economic decisions; these are political decisions that need to be made, whether all Australians are treated equally who have got disabilities or whether we continue with the same situation, where people are treated differently because, you know, they were born with a disability, they acquired it through an organic cause or because they're old, or trauma with no compensation.

MS SCOTT: John, have we finished with Joe, do you think?

MR WALSH: Thanks, Patricia. Yes.

MS SCOTT: Joe, thanks very much.

MS SCOTT: I now call to the table Irene Kwong.

MS KWONG: I'll just read the notes that I've written, and I think you've got an exact copy in front of you.

MS SCOTT: Thank you.

MS KWONG: Thank you, commissioners, for hearing my views. I'm just going to give you a straight profile of my life. My disability is cerebral palsy from birth and I'm 67 and a half years old. I rely on a motorised wheelchair for my mobility as I've got no balance at all, and the use of my left hand only. Working for a wage over a 44-year span I've never had an award wage or a full-support entitlement because of being employed in the disability sector. I value my ability to work and as an indication of my commitment to my job I have accrued over 3000 hours sick leave. During this time Centrelink's scrutiny has made me feel like a criminal carrying out my job, with all the hardships that that entails, while people receiving the dole, et cetera, like single mothers, are required to find work and are physically more able to do this but languish for years because of circumstance or choice. I wonder.

Where is the monetary reward for the extreme effort of people with a disability who undertake employment? Having said that, I appreciate all benefits and support I take advantage of, but I find it extremely difficult to manage on the money I receive, either from my wage or entitlement, to have a real quality of life, much more so now because I live in permanent care and have done for four years, in aged care for 16 months and disability care for two years, with the fees that high-care-needs people are required to pay.

Additional costs of my disability. If it wasn't for extremely careful management of my money over time I certainly wouldn't have been able to afford this care. When I wrote this part I thought, "Gosh, I've got to get a life somewhere." I don't drink, smoke or use make-up. My only necessary expense is a mobile phone for my safety and the cost of the Internet, which is dial-up, for my work. I think twice about attending social events because even with half-price fares, taxi and a meal it costs way over my budget; while visits to family again require taxi travel, so I keep to important occasions.

My expenses include board and lodging, incontinence aids, only partially funded, daily travel to work, wheelchair upkeep - for instance, a puncture recently cost $90, $20 for the repair and $70 for the call-out fee. Medication as well as soap, toothpaste, et cetera; items required for daily living. Motorised wheelchairs are only able to be replaced every eight years, to my knowledge, but let me down on a regular basis long before that time, and, given that a wheelchair is vital to my daily routine, being in fact my legs, a breakdown is stressful and traumatic, notwithstanding causing physical discomfort waiting for funding for a new chair.

Indeed, any other essential equipment is just unacceptable, not to mention the endless red tape one endures, to find after months or indeed years that you just take what the manufacturer gives you. Even though you've gone through all the specifications under the sun, it's what they want to sell you. If I opted for an easy life, and doubtless I have more excuses than many, I wouldn't have joined the paid workforce, after working a 16-hour day in the family restaurant for three years. At my age I'm still asked why I don't retire. "While I'm able to contribute to society I will continue to work," is my reply.

The government of the day trumpet the recent one-off benefit and the rise in the entitlement, which, while welcome, was clearly not designed for long-term and is of not much benefit. If by chance you were in my place for a month, I think you would find it a challenge, financially and in every other way. Thank you for the opportunity to present my life profile. I hope by hearing my story your deliberations will come up with a better process to enable all persons to live their life in relative comfort, without the ever-present threat of living near or below the poverty line while living with a disability. Thank you.

MS SCOTT: Thank you. Are you comfortable to take questions, Irene?

MS KWONG: Yes, I am.

MS SCOTT: David, do you have any questions?

MR KALISCH: Irene, I'm just interested in your work arrangements and whether you had an opportunity to work for higher income or whether that was a difficulty for you.

MS KWONG: Earlier on, when I was in my 20s or 30s, those opportunities might have come up. I had about three opportunities through my working life to work in the community, but with the barriers that were then not taken away, as they are now, it would have presented a much more difficult life for me to undertake that work. Now that I have been ensconced in the disability sector, I have actually moved between those sectors. Working for 23 and three-quarter years at one facility, I was offered a job last year to transfer to a day centre as an admin officer or assistant, so I took it and today actually marks a year since I changed my job.

MR KALISCH: Can you give us a sense of how things might be different today, with that change of employment, compared to what you were doing in the disability employment sector?

MS KWONG: The whole of my working life, with paid wages, I have been working in a business setting, either doing production, packaging, or things of that nature, and switchboard work and admin work.

MR KALISCH: Just sort of thinking back to the earlier years and some of those barriers that were issues at that stage, for getting into open employment?

MS KWONG: Right, well, when I left school I was 18, and that was in 1960. I went to the Commonwealth doctor to be assessed for my pension and he said to my parents, "There aren't any jobs out there for your daughter. So just take her home and utilise her in your family business, or whatever." So that's how I got into the family business anyway. You might ask how I worked for 16 hours a day. Well, in a family business, you do.

But we had a wholesale dim-sim and chicken roll business as well as the restaurant, so each day I was required to pack 200 dozen dim-sims into metal trays to be cooked; and you had to arrange them just so, otherwise they'd stick together, and I'd be in trouble. So that went on for three years. My dad passed away in the interim, and, after being home for 10 months helping mum around the house, et cetera the social worker got me into what was then the Spastic Society of Victoria, now Scope, and I've continued to work there ever since. But I'm representing myself today, not the organisation.

MS SCOTT: John, do you have questions for Irene?

MR WALSH: Yes. Irene, congratulations for spending 50 years in the workforce, it's unbelievable. I'm interested how you've managed for all that time in your care and support needs, and you mentioned that one of your major expenses is travel to and from work.

MS KWONG: Yes.

MR WALSH: How you manage with your travel and how you go about your daily life I guess would be interesting to me.

MS KWONG: Before I had to go into permanent care I lived at home for 57 years with my mum and I had the in-home support care. When my mum passed away four years ago the in-home support care still kept going but between 10 pm at night and 7 pm in the morning there wasn't any funding for people to stay with me overnight, so that meant that I had to stay in my bedroom with only the telephone and an automatic door for safety if anything happened, and my brothers and family thought that was just too dangerous to carry on with; even though I didn't, they did.

But the thing that moved me out of my family home was that I got shingles and the agency staff didn't like coming to support me because they thought they would get shingles as well and also be off work, and they couldn't afford that. So immediately after that my brothers contacted 50 places to try and get me high-care support, and finally I was able to get a position in an aged care home.

MR WALSH: What about travel, how do you go? Do you use public transport at all?

MS KWONG: No. The only way I can travel is by taxi, and it costs me up to $400 per month, even with my half-price taxi fare.

MR WALSH: That must put a big hole in your wages.

MS KWONG: It does.

MR WALSH: Can you tell me, Irene, how do you feel you've benefited from working all this time? You're incredibly positive, and I'm just wondering what keeps you positive.

MS KWONG: Probably having a Chinese background, and your mother saying, "You can't just sit back with your disability and do nothing about it. You've got to look after yourself as well as everybody else does. Just because you've got a disability doesn't discount you from doing work, so get to it."

MR WALSH: Fantastic.

MR KALISCH: Just on that, we heard some similar comments yesterday, from parents as well, who had a similar perspective, although they weren't Chinese.

MS SCOTT: Irene, can I ask you about your chair. You've said that you understood that you had to wait eight years to get it replaced but sometimes it would wear out before then or you'd need a different chair. How do you go about getting another chair if you're not eligible for government funding for that very specialised chair?

MS KWONG: This chair in the last month has let me down three times. I might say, at a strategy meeting that I had to attend all day it let me down. So I had to get the gears disengaged and someone had to push me, which was bad for them, because it's a heavy chair, and since then it's let me down three times. The repairer says they can't do anything about the switch, I've got to get someone to push the switch in and jiggle it around till the motor works. Well, I can't be let down like that. I've got things to do and places to go and people depending on me. This is why you get such aggravation when you chair breaks down.

MS SCOTT: But have you ever had to find your own funding, use your own money, to get chairs?

MS KWONG: Yes. This chair was funded up to $8000, it was $9200, and so I had to find the difference.

MS SCOTT: You indicated that sometimes they don't last the eight years.

MS KWONG: No.

MS SCOTT: So what happens then; let's say your chair goes kaput?

MS KWONG: They just keep repairing it all the time or they fast-track one that could take a year to get to you.

MR KALISCH: So you, essentially, pay for a lot of those repairs, then in the interim you're saying - - -

MS KWONG: Well, repairs are paid for; but funding for punctures and batteries aren't paid for, so you've got to pay it out of your own income.

MS SCOTT: John, do you want to ask any more questions?

MR WALSH: No, thank you. Thanks very much, Irene.

MS KWONG: That's all right. Thanks, John.

MR KALISCH: Thank you very much, Irene.

MS SCOTT: Thanks.

MS KWONG: Thank you.

MS SCOTT: Welcome, Diana. If you could just identify yourself for the transcript and then we'll let you start off.

MS HEGGIE (S): Diana Heggie and I'm the chief executive officer of Scope and I'm here today to put forward some views in respect of this inquiry. Our final submission or the submission that will be Scope's endorsed will be a written submission ultimately.

MS SCOTT: Yes, thank you.

MS HEGGIE (S): I did send to the commission some dot points around some of the key things that I might actually speak to, so very briefly just in terms of who Scope is - and I won't go into a huge amount of detail on that - but it is a disability organisation supporting over 7000 people across Victoria and our client base is largely people with significant disabilities, so very high support needs. Our mission is to support people with disabilities to be included in welcoming communities. So we facilitate that participation, that's a key goal for the organisation. In terms of this review and the guiding principles for this review, and it was actually in your own document, but I think it's very important that the guiding principles of the review are asking the question about, "Does this reduce the barriers that hinder full and effective participation in society on an equal basis with others?" I think we have to constantly come back to that and in terms of participation in the community and inclusion in the community, yes, it's about person-centred empowerment and people having an entitlement and people having money. That's one part of inclusion.

I guess the other two very important features of inclusion which we can't forget are: is the community ready for that inclusion? So if we look at the kindergarten, is it fully accessible. But not only that, is the community within that kindergarten ready? Are the teachers skilled? Are there the appropriate supports? Are the attitudes right? Is the awareness of all the other children in there right? So unless we look at those three things: the entitlement; the dollars for support to support the child; the actual environment itself, so the school itself, and then the attitude and awareness of the community to embrace that, we're going to actually fail. So I think those three things are really critical and we need to constantly ask ourselves about this review. Whatever we put in place we ask ourselves that question, have we reduced the barriers that enable people to be included? Because, yes, an entitlement thing, it's one piece of it and it's a very important piece of it but it is one piece of the equation. I just want to put that up there.

The second or the third point - I think I've got about nine points and I will race through it because I know people want to ask questions. The whole issue of unmet need and funding gap and that we've got to be very, very careful. I mean, if we just look at disability support, transport, home modifications et cetera across Australia, we're spending $5 billion on that currently and there's an estimated unmet need of another $5 billion in terms of unmet or undermet need across Australia. I think it's very important that we just don't look at this as repackaging or redistributing the existing funding. It is really, really very important that we actually add up all of this and that we make sure that we've got the equation right otherwise it will just be repackaging and Irene's stories and other people's stories that we've just heard are going to continue with the same.

The other big question is who's in and who's out and that is a very difficult question and I do note it in your report and who wants to decide that. I guess I'm here to support people with severe and significant disabilities being in so that's a million-odd Australians and I do really want to support that because very often these people are very vulnerable, there's communication difficulties, their voices aren't heard so I certainly am endorsing that. And what's in, again that's a very interesting question too and we've had lots of debates about what's in and what's out and that's a very hard one too. But it has to be about those things that are about the barriers. So it's about the disability, what is it in that disability? Personal care, aids, equipment, transport, all of those things that actually are about barriers. They have to be in here in terms of that.

When: like, lots of people say, "When should we do this? When is the most important part in somebody's life to do this?" You can look at early intervention and a lot of people will be talking about early childhood and early intervention and the importance of that. But I think the other thing we need to say is that one of the areas that over the years I've noticed there are really critical points in people's lives. So whether it be early intervention, kinder into school, school to what happens after school, school into employment, employment, retirement. All of these points are very stressful points in people's lives and unless there's additional resources and supports at those transitional points - and we really need to think about that - I think we're not going to get it right either. Over and over again we see those crisis points and they're not well managed in the current system.

Assessment - and I'm no expert on assessment - you've got to have some kind of assessment here. What I would just ask is that whatever is agreed on across Australia that we get some validity, we get some inter-racial reliability, we get some sense of what could be seen as something we would all respect in terms of this because we've just got so many assessment tools across the board. If we do go with a national scheme I think the notion of equality - the fact that if I've got a child of three with a disability that's the same in New South Wales, Victoria and Queensland and we have virtually the same children, one child can get $1000 of that package of support, one in Victoria might get five and if you happy to be lucky and live in Western Australia, you could happen to get eight and half thousand of a package. So none of this stuff actually makes sense. We are only a country of 22 million people and we need to stand back and say, "This doesn't make sense."

The other thing we mustn't forget in whatever scheme or whatever way we look at this is that the funding to families around respite and things like that, we've actually got to really consider that as a very important part of this; the support networks for those families as well. Going back to that whole inclusive community bit, I just want to emphasise the whole education, research and whatever scheme - we can put incentives into the schemes to encourage changing attitude and raising awareness. We've got to think about this stuff.

What's my view in terms of quality and how we look at this going forward? We're supporting people with extremely significant disabilities, vulnerable people in our community and I believe very strongly that they should be supported by people who are well trained to support them. Yes, behaviour is incredibly important but as well as that is training and being able to actually assist people. One little aside to this that I just want to say is that we actually ran a nexus survey - and I got the results last week - about awareness and the attitude of the community around disability but we did throw in two questions and one was, "Have you heard of the National Disability Insurance Scheme?" and the other was, "Do you support the idea for a National Disability Insurance Scheme?" It was actually quite interesting, there were 423 people that were actually asked about it and we were actually quite staggered to realise that in this short period of time 4 per cent of that had actually heard of the National Disability Insurance Scheme. Isn't that just fantastic in terms of a huge starting point for community change? Can you believe that? That's very high in this short period of time.

The other question we asked was, "Do you support the idea for a National Disability Insurance Scheme?" Do you know what was the most staggering statistic here, that of those people who said they knew it - so there were 19 people in total out of that who said that they knew it - 18 supported it. How amazing is that. The government would like to hear this sort of stuff because in terms of a political agenda it's just fantastic. That is huge. We only go that a week ago. So I just thought that would be interesting for you today. I think that this review is amazing. I think it's got the opportunity to bring transformational change ultimately to people's disabilities and just to say that we're very excited and I'm happy to take any questions.

MS SCOTT: John and David, is it okay if I lead off for a bit?

MR WALSH: Yes.

MS SCOTT: Thank you very much for coming along and thank you for your short outline, that's very useful. In some ways I wouldn't mind testing with you, Diana, some ideas that we've heard over - this is our third day of hearing, so for two and a half days the three of us have been hearing a variety of themes and I wouldn't mind testing them on you. Sometimes we've heard fairly negative things about providers and people saying that providers have too much control in the system and that the individual finds it hard to get real choice. Could you comment on that, and I guess I'd be interested in hearing your views about individualised care, personalised packages, where the individual has the control of the purchasing power. Could you talk to both those two themes.

MS HEGGIE (S): I am actually a supporter of people getting packages and getting the allocation of money and then being able to go out and say, "What can you do for me here? I actually want to have this or that," or whatever. I actually think that is an empowering model. So from a service provider perspective, it's like any service in the community, isn't it, whether you're going into a restaurant or you're going wherever, and quality is in the eyes of the person who is receiving the service and not always easy to get it right. I'll tell you as a service provider it's not easy to get it right all of the time, it isn't, but I've got no problem. I would strongly support a model that allows the consumer to actually go out and select and buy the services that they want.

MS SCOTT: This might be a hard question and I'm happy for you to come back and say that you want to take some time to answer it, but what proportion of your revenue stream now would be due to people being able to use choice and use individualised packages to decide that they're going to go to Scope to get particular services, "No, wait a minute, we won't go to Scope, we'll go to someone else"?

MS HEGGIE (S): I guess the whole early childhood section has moved to packages, so that whole area is now in that.

MS SCOTT: We're moving from jurisdiction to jurisdiction, so sometimes - - -

MS HEGGIE (S): Okay, sorry.

MS SCOTT: When we spoke to some people in Tasmania, they said people are on individualised packages but they are also told who they had to have as their service provider. So I just want to check - - -

MS HEGGIE (S): Okay. I'll give you an example. With the day and lifestyle area, where we're supporting about 630 people, we had been block funded up till the start of this year. That has completely moved those 634 people. They've got letters saying, "Your package for your day and lifestyle is now 20,000," 24,000, depending on whatever, so that's about $12 million of business has just gone across to people being able to actually make those choices and they have got two or three choices about how they can actually manage that. They can go through a financial intermediary and have it done that way. They could say, "I don't want Scope to provide that service any more. I want to move," and they can do that. So we really are starting to see those choices being given to families.

MS SCOTT: Okay, good.

MR KALISCH: Is there a market out there already or is it just still a little bit early to actually test that?

MS HEGGIE (S): It's a bit early to see, yes, it's a little bit early, and I suppose it will take a couple of people who are actually going to say, "Well, I'm going to change now or try something different." I know we've had a few referrals from others and we've also got a few other people who are saying, "We want to try something else," so it's early days and people are testing it. The other thing is the models aren't - it's the costing of the models and the package that they've actually got. Say you get $20,000 for your day and lifestyle and you're an individual and you want one-on-one support with that money, one-on-one support will not give you a whole lot of day and lifestyle opportunities, so families are really thinking about that in terms of, "Will I move from that or am I happy to stay here where it's not so individualised but I get maybe more than I would with the $20,000 if we took it," so it's early days in terms of that, but it's the way of the future and it's the way all the day and lifestyle money in Victoria will be allocated into the future.

MS SCOTT: So that relates to early child care, if I understand it - - -

MS HEGGIE (S): No, this is the adult area.

MS SCOTT: As well, okay, thank you. So could you take on notice maybe, if you feel comfortable, that idea of what proportion of your revenue at the moment is subject to people exercising their consumer rights, I guess I'd describe it as. Do you think that would be a figure you'd be able to ascertain?

MS HEGGIE (S): Yes, I would be able to get back to you, but I would suggest it would be in the region of 60 per cent, but I would have to get back to you.

MS SCOTT: An estimate would be fine. One of the other things that a number of people put to us yesterday was that when it came to some provision of care - and sometimes they were talking about attendant care and sometimes I think it was broader than that - they were more interested in the attitude and aptitude of the person rather than the qualifications they held. In fact they were sort of cautioning the commission not to necessarily go down the road of thinking that everyone had to be trained to a certain certificate level or a degree and so on because sometimes the worst thing that could happen is people had been through training and through the sector and came with a certain set of learned experiences that they didn't necessarily find helpful. I know you've stressed the importance of training and education. You must have heard of this idea before. Could you talk about that from your perspective.

MS HEGGIE (S): I think from Scope's perspective and the group of people that we are dealing with and supporting, we would strongly support that people actually have - I don't know what the level is, but I would be very supportive of people having a certificate - I don't know what certificate - but I believe that we need to move to that, where people are qualified to support people with significant disabilities. The child care sector, look at that; nobody is going to drop off their children anywhere and not have appropriate qualifications and training to support them, and I strongly believe that people with significant disabilities, where we need to support them and meet them out in the community, that there should be a qualification there and that people should be trained.

MR KALISCH: Is there a difference from I suppose your perspective in terms of caring for children vis-à-vis caring for adults, where adults may be able to be more assertive in terms of their requirements and their needs, whereas children may be more vulnerable?

MS HEGGIE (S): People who are well able cognitively to make decisions in respect of their own care, that is actually different. An awful lot of people that we are supporting actually can't, so I think there is a difference. There isn't one size for the whole thing and I think there's a continuum here. But I'm talking about people who need assistance in two or three areas of their daily living. They maybe can't make decisions. I think it's really important that people are trained to support them appropriately.

MS SCOTT: John, do you have some questions?

MR WALSH: Yes, Diana, on this same theme, I'm wondering whether the services you might offer are to support those people with very high support needs who would be better able to take control of their lives themselves.

MS HEGGIE (S): Would be better able to take control of their lives themselves?

MR WALSH: You said a minute ago that there are lots of people who can't make decisions, but I think we've seen over the last few days that people with severe disabilities are saying that with the right supports, they can learn how to make decisions and I'm wondering whether that's one of the support services you might plan to offer.

MS HEGGIE (S): Teaching people with very significant disabilities how to make decisions?

MR WALSH: Yes.

MS HEGGIE (S): Quite often it may be that in fact it's the family or a circle of support around them that end up making the decisions on behalf of people, so there are very good examples around the world of that, those kind of arrangements, but there actually people who can't make significant lifestyle decisions. They may be able to make some choices but there are people who can't and they need support around them to make the decision on their behalf and what's in their best interests, and it's not the service provider in that case, it should be the people around that person.

MS SCOTT: What proportion of your client base do you think would be in that position where they might be able to make a decision about TV but not necessarily about - that they'd like to focus on swimming or they'd like to focus on some holiday activities? What proportion of your client base do you think really aren't capable of making decisions without having a circle of friends or a supported person assisting them? I'm not talking about a decision as to whether they're necessarily going to live independently, but a decision about activities. What proportion of your client base couldn't make a decision about activities?

MS HEGGIE (S):   So just simple activities as opposed to decisions about their money or their package?

MS SCOTT: I know I'm putting you on the spot but, unfortunately, you've come at a time when we've had a lot of people put views to us and this is a chance for us to ask a provider. I'm sorry, you're getting two and a half days of built up questions that other people have put to us. On activities, what proportion of your client base couldn't make a decision on activities that they would be interested in?

MS HEGGIE (S):   That's quite a difficult one because over a period of time and with lots of support and lots of whatever they may be able to make a decision about swimming but it wouldn't be, "Do you want to swim?" and there would be a discussion between you and I about that. It would take a lot longer to get that answer through experience et cetera.

MS SCOTT: Sure.

MS HEGGIE (S):   So in terms of the proportion that would be able to make on basic life activities, again I would have to maybe come back to you on that.

MS SCOTT: Okay. But would I be right in thinking that maybe 50 per cent of your client base - - -

MS HEGGIE (S):   On basic life activities maybe 65, 70 per cent.

MS SCOTT: Let's work our way up the hierarchy of more difficult decision. What would be a more difficult decision, degree of independence or money management?

MS HEGGIE (S): Yes.

MS SCOTT: So basic money management, how much should we set aside for this amount here, how much should we set aside for that? What proportion of your client base could make that sort of decision?

MS HEGGIE (S): Probably about 35 per cent.

MS SCOTT: That's helpful for us because in terms of thinking about individualised packages and support arrangements that's quite helpful to know. Getting back to John's question about with the system moving more towards personalised care and individual packages and a greater focus on community involvement and social inclusion, is there something Scope is doing to ensure that the client base you have are as best placed as they can be to be able to actually be making those decisions given their capability? Is there some program that you have that is preparing them and increasing their capability for making those decisions?

MS HEGGIE (S): We are looking at how we best can support people to actually be empowered to make decisions but a lot of it has to do with also them having people around them and people who can make those decisions. So we certainly are looking at that and that's the best thing that can happen, that there people are around those people who aren't able to make those decisions and they make decisions for them in their best interests. It's not up to do it. It's about ensuring that those people are around those people. Yes, there are a couple of people who have nobody in their lives but it also shouldn't then be the service provider - the service provider can have input if they've known them for a very long time but there should be another means for that.

MS SCOTT: I've got some more questions but I don't want to monopolise - - -

MR WALSH: I just don't want to leave this one for a second, if you don't mind. Diana, without divulging any competitive secrets or anything, what would your view be about the direction Scope might take to maintain or expand its market share in a world of disability services like a national disability insurance model or even a person-centred funding model?

MS HEGGIE (S): One thing I'll say is that strategically as an organisation we have very much stuck with the focus of supporting people with disabilities. A lot of other organisations have expanded and they've gone into all sorts of other areas. But we have very much stuck to our original mission so it is about supporting people with disabilities. In terms of gaining market share, you're only as good as the service provider you are yourself in terms of gaining that market share. So in terms of us moving to being a national organisation, if that's the questions you're asking, at this point in time strategically we haven't - services actually really are more often than not chosen at a local level and you just look across the states, the more local a provider you are, the more likelihood of actually picking up the provision of services.

MS SCOTT: Diana, just going back to this, with more of the money going to the individual families and, in some cases, individual customers and them exercising their market power, it could be the case over time that your organisation actually becomes smaller, couldn't it?

MS HEGGIE (S): I guess what you can look at is that private providers start to come into the field and the whole market approach - there's a down side to that because people cherry-pick the areas that are going to make them the most money. We've actually got to watch that in terms of what ends up happening. So you can just end up with the most difficult and complex cases being left for the not-for-profit provider to pick up. So I do think there is a bit of caution that we need to take here in terms of the pure market approach.

MS SCOTT: It could, alternatively, be an opportunity for you to rehone your services to in fact win more of that market. I guess that's where John's question is coming from in a way, isn't it, what are you doing to think about your market?

MS HEGGIE (S): We're actually trying to focus on the quality of the service that we actually provide on the ground and we're putting a lot of energy into trying to get that workforce with the right behaviours and attitudes with the appropriate training. A lot of people with disabilities - one of the biggest criticisms is in the turnover of staff on a constant basis so they don't have the consistency of support being provided and we're really put a lot of effort to look at that and see can we actually stop that and enable the people working on the ground to enjoy, feel fulfilled in their work, to be given other opportunities in terms of their own skill development so that they actually do stay with us and that they are able to continue to support people on the ground. So we're actually rather than going off and saying, we're going to grow, we're going to take a big market share, we're going to go national, we're actually focusing more on trying to get the quality of what we deliver on the ground right and the issues of growth and that come as a result of you doing it right.

MS SCOTT: Just on that, you made a point right at the start that there was this incredible level of unmet demand and I would have to say that that's a theme we anticipated we were going to get and we certainly have got it in substantial numbers during these public hearings and already in our submissions that we're starting to receive. In some ways because there's that level of unmet demand, if in fact we find the government increases funding substantially in this sector, what's your capacity to actually gear up substantially - - -

MR KALISCH: Yes, to gear up substantially for that much larger group who would have funding for support. What's the capacity for the sector to respond quickly or would there need to be a transition in terms of meeting particular priority group needs first?

MS HEGGIE (S): You know the story about the sector capabilities across Australia and there had been a lot written and lots of reviews and 364 providers in Victoria, all sorts of sizes and arrangements and is the capacity of that sector able to substantially grow? I think that there's a lot of efficiencies to be had in that. What it looks like and how it transforms I won't talk about that today, but we've got to have client choice, but we've also got to have a vibrant and a sector that is able to support all of this. Is the sector able to do that right now? No would be my view. There are certain organisations that are better able to do bits of it, but is it where we would want it to be? No.

An awful lot of the infrastructure has been allowed to run down over many years. People will know that there was a big review by PricewaterhouseCooper down here in Victoria about how the government currently buys services from organisations. The government will say to us, "We want you to deliver so many hours of therapy and we'll pay you $64 an hour," but it costs $89 and the actual reality is there is always a gap to be filled here. The not-for-profit sector has done that through a variety of means. They have used businesses, corporations, philanthropy, volunteers and all of these things come into play here to actually fill the gap and that's a cost that has to be built into whatever is happening in this review.

MR KALISCH: You talked a little bit about potential for cherry picking if you move towards more of a market based approach where private providers, for example, might come in and I presume not-for-profit organisations might also come in and choose particular area of activities that might be more revenue inducing. Is that a real issue or is it something that is just feared? Are there examples of where it has happened to date that we can be aware of?

MS HEGGIE (S): No, because there's not a lot of for-profit providers in this sector but it certainly is a fear and particularly the for-profit providers because of their commercial astuteness they understand their costs down to the last hour and cent and so they will work out fairly quickly where there is a bit of a cash cow or a bit of a whatever and they'll be in there like Flynn. Unfortunately, the not-for-profit providers are lagging behind and a lot of them don't even understand their own costs.

MR KALISCH: Is that actually a dimension where the not-for-profit also needs to pick up its game in terms of its professional management?

MS HEGGIE (S): Hugely. It's like an accounting or a legal firm. I mean, they all know what their costs are and what they're going to charge and whatever. The expectations from people with disabilities in family members is that we're all able to do that and that we can say, "If you want to be supported to go to TAFE and you want to choose a provider to provide you with your personal care or do your scribing at the TAFE, what are you going to charge me" - who is the consumer now, the customer - "to do that?" The capacity of the sector to do that - the PricewaterhouseCooper review was pretty scathing on the sector's capacity to understand its own costs. So, yes, there is all of that there.

MR KALISCH: Just one more question from me just in terms of the capacity of the sector to expand. Is the sector best placed to deal with people with more moderate or modest disabilities as opposed to those who have high support needs? Is it concentrated in particular areas of specialisation and people's needs at the moment or is it just unmet need across the board?

MS HEGGIE (S):   I think it's more unmet need across the board actually.

MR WALSH: Just one last one, Diana, and changing tack totally. I imagine you have a large children client base and we've heard a lot about the potential for early intervention with children with particularly autism but also intellectual disability. I am just wondering if you've got any views on that potential.

MS HEGGIE (S):   I think the research on supporting children in the early years and getting in there early and putting in the resources is there and it's very solid and I would be a huge supporter of that. One of the problems that families are saying is that where they choose to have children integrated into schools - I mean, we actually have a large therapy team that go into schools, that the school buy from us for our therapists to go in to support the children in mainstream school. It's very significant. We support about 2300 children across schools who are in integrated schools and the biggest criticism is that they just don't get enough support in the mainstream schools, so there's not enough support and so families get incredibly frustrated and whilst they may want the inclusion to work, the supports aren't necessarily there.

Those three things that I spoke about earlier which was, yes, there can be the package but the school has to be totally ready and the students have to be ready and that's all about resourcing and it can't be done without money and that's where these things fail. I think early intervention is extremely important. If I were to put resources and supports anywhere, it would be there but also those transitional points and the like that I spoke about earlier. They're always forgotten and they've very critical for families, very critical, and for people with disabilities and very stressful.

MR WALSH: Is there the potential for support in preschool ages? We've heard that support is needed for children as young as two years old.

MS HEGGIE (S):   Yes, and I think in things like kindergarten and things like that supporting them to be integrated in the kindergarten I think it's really, really important that that actually happens early on. I mean, the younger the children - the primary school, the awareness raising, really important. There's nothing like people with disabilities going into the schools and really talking to the children about it. Over time then it's just a natural occurrence and kids will be supported in schools with significant disabilities.

MR WALSH: That's it for me, Patricia. Thank you.

MS SCOTT: In your introduction you referred to a number of the questions we've asked in the issues paper. You referred to assessment, you made the point that you hoped there would be some sort of agreement across Australia and then in relation to the definition and eligibility criteria you pointed out how problematic that was and you didn't exactly say good luck, but I have to say that seemed to be a bit of an undercurrent there. I'm interested to know whether Scope in their submission would actually be saying what they recommend to the commission in terms of eligibility, in terms of assessment, in terms of those things because we've had a number of people come here today and they're not all well resourced and I appreciate you've got a number of pressures on your organisation. But if we throw the questions out and you throw the questions back, someone still at the end of the day has to write the report.

So I guess I would be either asking as a question now or certainly encouraging you in your submission to chance your arm to actually give us answers because in some ways we need groups like yours to put a marker in the sand so other people can react. There will be people here today who may very much support what you've said and I think somebody wanted to asked a question. But one way to react is in fact just to put another submission in to what you hear, if you haven't heard something that you liked in any of the submissions that we've had today or in any presentations we've had today. So, Diana, do you feel that you could say now whether you're going to be definitive in your submission in answer to those questions or do you think you're going to, to be frank, fudge it and find that the commission doesn't have - you know, you're a major organisation in the disability sector. Where do you stand on this issue now?

MS HEGGIE (S):   We're certainly going to endeavour to put forward solutions and proposals but it is actually very complex. Sometimes it's not all that easy to be black and white on some of those things. We are certainly going to look towards answering the questions that have been put out. I do need to get board endorsement in fairness.

MS SCOTT: That's perfectly fine. I guess a reminder for those people that joined us later, we have extended the submission time to 16 August, so we're hoping that that will give people sufficient time to actually answer those questions, so we'd certainly welcome that. Diana, thank you very much for your time today, that was very good.

MS SCOTT: That's the end of the people who have identified that they would like to make a presentation to us. Is there anyone now in the audience that would like to come forward and say something who haven't had an opportunity beforehand? George, you'd like to have a second go. Is there anyone who has been sitting back and thought, "This is my chance in life, I might just make a few points." No, okay. Is there interest at the back? George, if we gave you five minutes, would that be okay?

MR VASSILIOU: Yes, I just wanted to add - - -

MR KALISCH: If you could come to the microphone so then we can get it on the record.

MR VASSILIOU: Thanks for the second opportunity. I just wanted to make sure that the commission understands the understandings that people have of what is a consumer-directed model of care or the individualised approach because it has different meanings to individuals as it has to organisations. I want to put the understanding that we have as a family about what this actually means. Normally an organisation when they talk about an individualised arrangement or packages the money comes to the organisation but the provision of supports is outsourced to another agency and that agency comes into the home or supports the individual either in their home or in some arrangement that that person has, whether they're living alone or with a family caregiver.

The way we understand it is that the control of those funds is totally under the control of the family or the individuals themselves. Services are not bought by outsourcing or through outsourcing. The family or the individual actually contracts with the provider or the employee in a sense to come in and provide support. That is a very great distinction because we're talking about costs.

MS SCOTT: I just want to check, in one model the money goes - let's say the package is $8000, the package goes to you or your daughter. In another model Scope or Yooralla, someone says, "We've got these particular clients," and somebody parcels bundles of money to that organisation, they're notionally allocated for individuals but then the organisation still has control of those moneys. What you're cautioning is when we're talking to people, make sure you know when they use the phrase "individualised" or "customer" whether the money is in their hands or in your hands.

MR KALISCH: Certainly in the instances that have been brought to our attention people's examples have been very much around the individual with a disability or their family having control of the money. So it's been very much in that one model.

MR VASSILIOU: I just want to stress again what control actually means. I think we need to make it explicit that the individual has total control of those funds and in essence for any administrative support or bookkeeping-type support to keep track of wages or super or WorkCover and so forth, that person contracts with an agency to do that and they pay them a fee. I just want to use the ratio that I referred to before, in my experience it's an 80:20 or 30:70 split depending on who you speak to. In most cases organisations could spend up to 70 per cent of the actual package allocation on administration, case management and the term that I used before, ancillary. In my experience I have been able to turn that around and get a greater proportion of that funding allocation to buy direct hours and this is where we want to focus on, getting the biggest bang for the dollars from the available sources of funds.

The other aspect included in this definition of consumer-directed models of care is looking at the outcome. How do we value, how do we assess the quality outcomes from that self-control because that is not necessarily factored into how we view these arrangements? The report that I have is once people become masters of their own destiny in a sense or control the package they buy, they form relationships with employees they choose, they welcome people into their homes, that is a positive outcome. If you rely on an agency to outsource to another agency and that person doesn't turn up, who do you turn to? Do you go back to the fund holder, do you go back to the outsourcing agency? It creates a whole lot of issues that the family sometimes doesn't want to buy into. I've had families say to me, "George, we have to manage the case managers." These reports are quite horrific in a sense but it happens.

I want to stress that consumer-directed models of care are not only for those who are competent. Families, together with their disabled person who has profound disabilities can get best value for the dollars here, so shouldn't be limited but it is an option let me say.

MS SCOTT: Thank you very much. Yes, you are welcome. Come forward. Just identify yourself, if that's all right.

MS ROBERTS: My name is Bernadette Roberts. I work at Scope and I came here today out of interest and for work reasons but my story isn't necessarily Scope's, it's a bit of mine.

MS SCOTT: That's fine.

MS ROBERTS: We heard today from Angela who was from Benalla and I was actually her therapist and to see her today was something that I never, ever thought I would see her achieve so much with her life. I was talking to her parents and they recalled me after I told them I was the pregnant one who left. I actually didn't go back because Angela's story and her journey, I couldn't go back into health. The way that the health care sector puts barriers on people with a disability - people who come in with trauma or with some kind of - they make a judgment way too early and there's no hope. After working in that sector for so long, I couldn't go back to it. But then I found the disability sector.

I just want to talk a little bit about decision-making. You asked some questions about decision-making and is there anything out there at the moment around supporting people to make a decision and it's supporting people like Angela and her family to make decisions when they're possibly in situations that they're not used to dealing with. At Scope there are a lot of different types of ways that we're looking at how can we support people with a disability to make decisions in a supported way so they're in control of the decisions and their support network is actually supported, trained, go through different types of things to actually build the skills up so that they can support the person that they care for to make decisions. There are a couple of programs that we've been looking at in the last couple of the years, one is called Out of the Box and the other one is Follow Your Dreams and actually can't remember the names of the people - they originate in Philadelphia and they are intense programs that bring people together. It includes empowerment and includes people actually learning how to take control - like, it's their decisions, it's learning that it's their decisions and it starts at that fundamental level and then goes on. That's really all I've got to say.

MS SCOTT: Bernadette, thank you very much for telling us your involvement in that earlier story. I also found that very uplifting, having seen the film about Angela shortly after the incident. You talked about that you were looking at Follow Your Dreams or Out of the Box. You're looking at it or you're actually implementing it?

MS ROBERTS: We have implemented it. It's not funded, this is something we get funding for and we have to go and get funding through donations, fund-raising and just very generous folk who want to see these things happen. We're lucky in that we have a speech pathologist at Scope who worked with the gurus in Philadelphia and was able to bring that training over to Australia. I think since then we have actually had someone who is another speech pathologist - and this is beside the point but she does actually have a disability and what she has done is she's gone over there and brought back some of this training as well. We're trying to expand that but it's not funded. It is something that is inspiring and people do go on to live out their dreams. One of the examples of this was there was one woman and I think she was from Geelong and from this she went to jewellery shops in Bourke Street trying on diamond rings and stuff. It was just something in everyday life but she had actually never been into jewellery stores before.

There was another woman, there's a photo of her I've seen and she's got a two-year-old on the back of her wheelchair who is going for a bit of a ride and a beer on the front and it's like she's just having fun, but beforehand never had. It is an intense program, it does cost a lot of money but people can make their own decisions if they're supported and if they've got those networks behind them supporting them.

MR KALISCH: I'm just wondering, Diana, whether that dimension can also be introduced into Scope's submission given the experience.

MS SCOTT: Yes.

MR WALSH: Can I just ask, Bernadette, you said it costs a lot of money. What's "a lot of money"?

MS ROBERTS: I think it was about $45,000 for two days, and it was a couple of years ago that we ran it. But I'm pretty sure it's around $45,000 for two days and I think there were about eight people who did it. That's off the top of my head, all those figure are probably wrong but it was around that. There is data, we've got it, we could give it to you.

MS SCOTT: Okay.

MR KALISCH: Per person it's not a huge amount probably.

MS ROBERTS: Their lives have taken on new dimensions but these guys aren't - you talk about early intervention, these guys that participated in it, the youngest person was around 18 but the average age is probably around 40. My belief is we shouldn't make decisions based on people's age, sometimes just given injections of funding their potential for life is huge.

MR KALISCH: Thank you.

MS SCOTT: Thank you very much. Thank you very much for attending today and especially for one or two individuals who have attended both days, that's very commendable. I now adjourn this hearing and the hearings will recommence in Adelaide.

AT 3.35 PM THE INQUIRY WAS ADJOURNED UNTIL
WEDNESDAY, 16 JUNE 2010