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TRANSCRIPT OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT BRISBANE ON THURSDAY, 15 JULY 2010, AT 11.02 AM

Continued from 13/7/10 in Canberra

INDEX

MS SCOTT: Good morning. Welcome to the public hearing for the Productivity Commission inquiry into disability care and support and thank you for attending today. My name is Patricia Scott and I'm the presiding commissioner of this inquiry. My fellow commissioners are David Kalisch, here in person, and John Walsh, who is joining us by Skype, but John will be participating in this inquiry. The technology, when it does work, works beautifully.

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

The Australian government has asked the commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. We have already talked to a range of organisations and individuals with an interest in these issues, and 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 in as early as possible, in view of concerns raised by participants for more time to consult, the commission has extended the due date for initial submissions to Monday, 16 August 2010. The commission welcomes second, third and even fourth submissions, including submissions after the due date, and these submissions may include additional points people wish to make, comments on other people's submissions or other organisations' views and the results of community consultations.

The purpose of these hearings is to provide an opportunity for interested parties to discuss their submissions and their views on the public record. Hence, a lot of our effort this morning to ensure that the recording will be right. Following the hearings in Brisbane we will be going on to Sydney and Perth. We have already held hearings in the other capital cities. We will then be working towards completing a draft report in February for public comment and we will invite participation in another round of hearings after that, so people have had time to read and consider the report.

We would like to conduct all hearings in a reasonably informal manner, but I do remind participants that a full transcript is being taken. For this reason, comments from the floor cannot be taken. But at the end of today's proceedings I will provide an opportunity for anyone who wishes to come forward and make a comment. So even if you ticked the box that you are an observer today, if you are interested in making a comment at the end of today, please feel free to come forward and I will invite you to come up. Unfortunately, you won't have that opportunity tomorrow, so this is the day to make the impromptu comments.

Participants are not required to take an oath but are required under the Productivity Commission Act to be truthful in their remarks. Participants are welcome to comment on the issues raised in other submissions or on anything you hear today. A transcript will be made available from the commission's web site following the hearings. Are there any media representatives in the audience today? No. That's fine.

To comply with the requirements of the Commonwealth occupational health and safety legislation, you are advised that in the unlikely event of an emergency requiring the evacuation of this building to please follow the instructions of the hotel staff; and if anyone needs assistance, please see Clinton, myself or David and we will be happy to help. There has been a small change in our program. One of the people it was hoped was to be presenting today is not available. So what we are going to do is start with Henk. I invite you forward, Henk. Thanks very much for coming along.

MR HORCHNER: Thank you, commissioners. I take it John can hear me all right.

MR WALSH: Yes, I can. Pleased to meet you.

MR HORCHNER: Good. Thank you.

MS SCOTT: Just for the record, Henk, could you state your full name and whether you're representing yourself or an organisation.

MR HORCHNER: My name is Henk Horchner, spelt with an "e", H-e-n-k. I'm Dutch born. I live at - - -

MS SCOTT: That's all right. We don't need your address.

MR HORCHNER: I thought I'd tell a little bit about myself first, because in the 50s I got naturalised, as a young teenager.   When I got naturalised, in those days, I was asked to denounce my loyalty to the Dutch queen; and then I stood there for five minutes and I'm not sure whether it was the King or whether it was the brand new Queen, it was just on that change, but I had to swear loyalty then to the King or Queen, and I have done this many times in my life.

At the time of the ceremony I was asked not to forget my past cultures but Alderman Lex Ord asked that we in effect put an input to society of what we had learned and what we brought to this country. I was quite moved by that and I have taken this to heart and I have been very actively involved, as some of the people here today know, in various activities with the community. One of those activities was to take about 200 children from different organisations to a picture theatre in town. We got the Brisbane City Council bus drivers to bring them in, and there they were in their stretchers with drips and broken legs and plasters, and we were very satisfied, two Lions who stood at the back of the hall and said, "We're really doing something good." All of a sudden I got a kick in my leg and it was a little Aboriginal boy about nine years old and he says, "I want to go to the loo." I said, "Okay," and I looked at Don, the other Lion, and I said, "What do you reckon?" He said, Oh, we'll take him."

So we both walked outside the theatre at St James and we walked to the toilet and walked up to the urinal and we did what men normally do when they stand in front of a urinal, and all of a sudden a little voice says, "What about me?" That's a little phrase, "What about me?" and I want you to remember that, because I looked down and there stood a nine-year-old boy who had no arms. So you can imagine when two adult men looked at each other for a fraction of a second what went through their mind, "How are we going to handle this?" Both of us, although no longer in Lions, remember that moment so vividly, "What about me?"

Over the years we got involved in all sorts of different activities. I'm a representative for Endeavour parents, although I'm no longer a parent, I lost my Down Syndrome daughter two years ago. I'm a coordinator for them and I look after about 350 families once a month with another coordinator, Kevin, who is present here today. We provide all sorts of advocacy and support for them, and numerous other activities. So that we have, very thankfully, been adopted by Endeavour as honorary life members, et cetera. But I won't go into these details, that's not important.

But, yes, I am a supporter of Endeavour Foundation, or for that matter, the entire disability sector. About 10 years, 12 years ago I became involved and I applied for a Churchill Fellowship to investigate accommodation and activities for people with disabilities. I was unsuccessful. But as a result, because I had a fire in my belly, I finished up taking an active part in researching the material and I came across numerous models on how they accommodated people with different disabilities, and I became very much involved in the Flemish model. My submission therefore, I have repeated what I gave to the department of disabilities, DSQ, in 2002 and what I have submitted as a 2004/5 for a Churchill Fellowship, and I brought it up today to 2010.

I'd like to believe that at the moment the NDIS is as a result of those activities from years ago where different people in authority have accepted what we had been saying at these consultation meeting, and I don't believe that they were really, truly consultation meetings. Consultations meetings here in Queensland are basically meetings to tell us what they want to believe we should follow. A consultation meeting is a very difficult process, and I feel very humble here today sitting as the first person in Queensland to be given an opportunity to address you at the public inquiry, which I believe is a consultation.

I'll make certain recommendations, if I may. Initially, whatever we're talking about at the moment, I believe the term "insurance" is wrong, because as soon as you mention "insurance" people get an impression that you've got to submit money in order to get a reward. I don't think that is correct. It is a right, the right of an individual to get the support. People unfortunate enough to be born to a set of parents where they were unfortunate enough to be intellectually disabled or to have an accident on a horse or in a car and therefore have certain disabilities have a right and I believe the entire scheme should be based on that premise. In other words, "What about me?"

Therefore I believe that everybody here that will be talking for the next two days should be talking not about themselves, not about the little circles above their heads but some of the little experiences about people who cannot talk on their own behalf. I believe we should tell some little stories. Yes, we can talk about this for hours, for weeks and for months, what the needs are of people with disability, and a lot of people more qualified than myself have already done this and it's available in a lot of different places, but it was only last night that I was reporting on a meeting I had with 12 sets of parents who came to my regular monthly meeting, and it turned out they were all in the 70s and 80s and one 90.

There was one woman who had rung up, 93, who apologised that she couldn't go, because, "Henk, I don't know if you know it, but my husband has now turned blind. I have got a driver's licence but I'm not game enough to drive, I'm too old." It reminded me how often we find when we're caring for people with disabilities, and particularly through large service providers, whoever they are, that sometimes we forget about, "How about me?" because those that are "me" quite often are now becoming the carers, carers of their parents.

Too often we see that we provide service and backup where we think it's suitable to the people with disability. But we often forget those people who care for them they are now turning old. Like I said from the start - I'm 77 - I've got a fire in my belly. But the thing is we do forget that we're all getting older. In this morning's paper - people have forgotten - there is a funeral notice for Les Patman; nobody mentioned that he used to be a past lord mayor of this city. Les Patman was 93. Because we turn 65, we retire, we are forgotten.

Therefore I believe the NDIS is not just a responsibility for the disabled but also for those who care for them, because they are part of that community. So the entire scheme should not only look at one section of the community but what the effect is to the entire community. I believe they should start registering a lot of the officials and the people who come out of the universities who say, "Oh, you shouldn't put them in boxes." But let us face reality, in case you want to make a judgment as to what it costs to provide the services which really they are entitled to as a right, you have to know actually their requirements. You can then make an adjustment as to, "Oh, well, we'll go this way," and "We'll go that far."

We have got trouble with the English language where we often mistake words, like when I mention about the word "insurance"; the intent is right, but we can't find a right word for "insurance". You heard the commissioner making a comment that it includes accommodation, but if you look closely at the NDIS they make reference to it doesn't include housing. In my limited language of Dutch and English, with "housing" and "accommodation" there's a very close connotation. So we have to be extremely careful when we work on anything that we use the correct terminology and that we are consistent.

We are dealing with a very large country of numerous states. So therefore when there's a national program we should make it that it is applicable to every part of this lovely country. You often hear statements about designs of buildings. When I was overseas - and the commissioners will understand - I took certain photographs, when I was there prior to the Churchill Fellowship, and I took them of different developments. I was the Australian bicentennial coordinator for the Brisbane City Council and while I was over there I did numerous studies on the different topics they asked of me.

One was high-density accommodation. In the submission I have put two photographs and they are basically a little settlement of concrete balls, if you can see the concrete balls, as a home, placed on top of a concrete cylinder, and each one is like an individual home. I have put them in the submission as an attention-seeker, because I have got a photograph, one of these balls and a beautiful moon above it; but let's look at it the other way, the ball could be taken from Mars, looking back at the world. I want to clarify to the commissioners that it is not my intention to put all of the disabled people to Mars, but we have got to face reality as to what we are, "What about me?" I recognise I only got 10 minutes and I am already far beyond that, I'm sure.

MS SCOTT: You're coming up very close to it, I think.

MR HORCHNER: Very close to it. So I've got to be selective.

MS SCOTT: Can I ask if you would you be comfortable if we asked you some questions?

MR HORCHNER: Yes. I have been told that the Queensland state government - and there are people present in the audience that can confirm this, or clarify this - no longer wish to allocate individual lifestyle packages and that they only want to go to block funding, and that creates all sorts of problems if you're starting for the whole of life, because if it's block funding and not to the individual what about if they have two or more different service providers.

I know one set of parents, present here today, that uses more than one service provider: those that they look after themselves in a unit, those that provide the care in that unit, the supply of mails, the outside activities during the day, all different types of service providers. How do you allocate the block funding in this? So therefore be very careful on this. Two days ago I realised all of a sudden that you would be asking me questions and I believe that the time of questions is more important as to what you need to hear.

I would therefore finish up by saying I have got a fire in my belly. It doesn't matter how old I am. Most of you know that I am very dedicated to community and I'm a networker, I work for the community. So I say to you, commissioners, I make myself available as a pensioner, I'm prepared to work full-time for this scheme in any duty that you might allocate to me. All I ask is that if I have got any out-of-pocket expenses I get reimbursed for it, because I'm a very old pensioner. Thank you for listening. I feel very humble in this. But don't forget, "What about me?"

MS SCOTT: Thank you very much. You have obviously got strong supporters out there. John, would you like to start off your questions.

MR WALSH: Thanks very much, Henk, and I appreciate your passion. I have read the written notes you provided to us today and in it you talk fairly extensively about the Belgian/Flemish model. One thing you talk about there is a regional evaluation committee for deciding who qualifies. Would you mind just talking a little bit about whether you've seen that overseas and how it works?

MR HORCHNER: Yes. The submission, for those people in the audience here, I've done in three sections. One was more as a summary, and, answering four questions from the health council, as you'll notice, I twisted the wording a bit to make it applicable for disability. The second part is basically the development of the Flemish model in Australia. The third volume was in relation to the history, as to where I got the information and some official records on how many years it took for the Flemish model to be established.

In it I also gave a history on Belgium itself, how it has numerous provinces and different levels of government, how they have got the five levels of government and how difficult it is to get a national policy there on people with disability; although they are governed by an overall Belgian government. This is basically because over many, many years Belgium has been under Dutch, Flemish, French, English and all sort of different governance. You will find most of the communities in Holland use Belgium as a model.

You ask me about professionalism, it is basically because of the different levels of government and the different divisions - or, states, you might say, they are actually called provinces; they need different organisations on how to assess the people if they are entitled to disabilities. But the government is not doing it, they in fact install a committee in each of the provinces - with an independent commission, I think would be the proper translation for that. Does that answer that, John?

MR WALSH: Yes. Thank you. The central government allocates money to each of these regional areas?

MR HORCHNER: Yes, it does. But I must admit that over the last five to 10 years I haven't been updated as to the amount of moneys that are short. But I do know that at least they have a registration, they do know what they are up for but they are still waiting for the full, because, as you'll notice, when they started talking about the argument about prisons - that they had a lot of people with disability in prisons, because of certain sexual problems with people's intellectual disability - they still have service of people with disability in prisons and they want to get that finished with. So they are still short of money, as such.

MR WALSH: Thank you.

MR KALISCH: Henk, I was just interested in exploring these international experiences a little bit further, building on what John has asked you. Are there regional differences, in terms of what services are offered and how they are paid for, in your experience of Belgium and Holland?

MR HORCHNER: I made reference earlier in what I said here today to how difficult it is sometimes to find a suitable word in English to describe a certain situation. In other languages, such as French and Flemish - Flanders is more as a dialect of Holland - you can say certain things four or five different ways to give it different shades of grey or black between white and black. I am not a linguist, so therefore I can't give you exact information. But "housing" and "accommodation", how we use different words is very difficult sometimes.

How should I put it? One major experience I had in my life might explain this. During the war I was a refugee. A doctor gave me two weeks to live. My mother took me on a pushbike on a highway and we're pedalling along, the bike was six inches too high, the front was a garden hose, the back was all different inlays outside the tyre. There were thousands of people along the highway, some were lying on the side. It was slightly snowing.

I was getting very sore in the bottom because the bike was six inches too high, so my mother encouraged me to hang on to a horse and cart that came up so it would pull me along, and the fellow put the whip me on me, because, you know, he was thinking of himself.   Five miles later the horse actually had died on the side of the road, and I was there when the public that was walking along the road cut its throat and actually drank the blood because they were that starving. A little bit further my mother threw me her scarf so she could pull me along. She at the time was three months pregnant. She pulled me along on this scarf.

All of a sudden these people alongside the road stood up and cheered. They said something only a Dutch person can understand, which is, "Orange be above all. Long live the queen." We couldn't understand what it was. We looked around - and I can remember looking around - and all of a sudden we realised what it was: my mother was pulling me along with an orange scarf. So, finishing up, I'll let you know I was nearly wearing an orange shirt here today, but we didn't win the final. Yes, I have studied models in Canada. I have studied the model in the UK. I have visited people in Holland, I'd love to go back and do a study and try to answer the questions you are trying to find.

MR KALISCH: Do you think that there should be differences between states or should there be the same service offer?

MR HORCHNER: No. We're all Australian. No hesitation. Too much of this state against state. We're all Australians, and I must admit I may be a bigger Australian than most of you because I've got a bigger piece of paper to prove it than your birth notice.

MS SCOTT: John, further questions?

MR WALSH: No, I'm good. Thanks, Henk. I appreciated it.

MR HORCHNER: I know there are people here - I know the individuals - we can talk and have talked for years about this subject and we continue to talk. All I ask you is, in your recommendations set definite guidelines and definite dates. Even although your report might go in February, try to set a date preliminary and put a date of 1 January even before you put the volume out. It's important that the community accept the responsibility that the person with a disability has a right so that we take care of those who say, "What about me?"

MS SCOTT: Thank you very much.

MS SCOTT: Thank you. I'd now like to invite Pave the Way and the Mamre Association to come forward. Catherine and Jeremy, thank you.

MS RAJU (PTW): Thank you, Commissioners, and thank you for the opportunity to speak to today. I'm Catherine Raju and this is Jeremy Ward from Pave the Way, which is a project within the Mamre Association. Just a brief introduction to our work. Mamre Association is a family support organisation in Brisbane that's been working for 23 years with families. Pave the Way is a project within Mamre that has been going for about seven years now in a part-time and now a full-time basis. We largely work with families I suppose generally in the area of succession planning, really looking at the question of what will happen when we, as parents, are no longer around. So I suppose I work on a state-wide base and again I make that point that that's different from Mamre generally, which works only in Brisbane. We do work throughout the state of Queensland.

It's really about the background thinking to that big question which we believe is really about being very clear about what it is that people hope for for the life of their son or daughter, or brother or sister, and then to take the steps of planning to put that vision for a good life in place. The work that we do with families in that regard, then, is supporting that work through information which includes legal information around estate planning and guardianship and administration issues. We work on the level of workshops and information sessions for families, and also work with individual families in planning, whether that's in an informal conversation or whether it's a more formal structured planning session that they invite other people to.

We have an extensive mailing list of over 1300 people throughout Queensland which is to the very large extent families and individuals; a few services are on that. I suppose just to look at that word "planning" which we will talk about again a bit later, when we talk about planning we're really, I suppose, working on the level of what we call "whole of life long-term planning". A lot of families are involved in planning at a service level through IEPs or service plans for individuals, services that they're involved in, and that's all important. The planning we're talking about is, I suppose, family driven, starting with the family and the individual and outside services; looking at services as a part of the overall plan but not something that drives the planning. So that's important when we talk about that a bit later in our submission.

So just as regards the submission, which we appreciate is a very comprehensive pulling together of the very complex issues in this whole thing and we could have spent a lot more of our resources in planning a very detailed response to every one of the points here, but for the purposes of this verbal submission anyway we have picked out just a few of the issues that we relate to particularly in our work and that, as I said, is around the idea of the need for an underlying vision for this whole national disability support scheme, a philosophy, if you like; the importance of life-long or succession planning services for people involved in this; and, as Jeremy will speak about particularly later, the notion of taxation relief for families as part of this whole scheme.

So for the first point, this relates particularly to chapter 5 of the submission, the key design elements. I think the point that we just briefly want to make here is that we believe for this scheme to really make a profound difference for people with disabilities that it needs to have a underlying philosophy or vision about the life of people with disabilities that drives it - if this is going to truly make a difference for people. I think the things that are indicated in the scheme so far - the issues about who makes decisions, who is it for, what benefits there are, the amounts, and service delivery et cetera - are highly important and they are core design principles as you describe them, but if there isn't something driving what all of this leads to, then I think it runs into the danger of simply becoming another way of shuffling the money around.

Certainly there hopefully will be more money and perhaps better allocated, but if that vision or philosophy is not there, then it really runs the risk of not actually making a profound difference to the lives of people with disability in the end; that there will be nothing much new that will result of this. I think that relates also to one of the questions in the governance issue in chapter 12 which is about the workforce that will need to be built up because certainly there is a likelihood that new services would be developed to meet the demand of people who have got the ability to buy services, if you like, however that happens, but again, if there isn't some philosophy or vision about what is possible for people with disabilities driving the development of services, then it will again simply be the case of more of the same and without anything changing much. So I think that is a key element to what we want to say in this submission.

So Jeremy, I think, would like to talk a bit about the exclusion issue from chapter 6 - if you wanted to deal with that.

MR WARD (PTW): We just wanted to make a couple of points around the question of who should be eligible in chapter 6 of the issues paper. We note that the Commission has discussed the issue of the terms of reference appearing to restrict your focus to people with severe and profound disabilities and we would simply make the point that we would have huge concern if people who are labelled with mild and moderate disabilities are excluded in some way. Often a very little bit of appropriate support with some good planning can go an enormous way to make a difference for people who are relatively capable as compared with those who might be less capable. If the scheme is to replace the existing funding arrangements, then it follows that a whole lot of people are going to miss out because people with mild and moderate disabilities are getting some support at the moment, maybe not very much and it's very hit and miss and so on, but it's out there.

The next point we wanted to make was that in the work that we're doing we're very keen to support families to build networks of people. We believe that people keep people safe, so we believe that in the long term the best thing that families and allies can do is develop a sound network of support around - especially the vulnerable people with disabilities, especially those with whom the commission is - obviously been asked to deal, as with the severe and profound disabilities.

So in the design and implementation of any scheme we would want to see that the role of families and allies is very much respected and involved at all levels, not just in the so-called caring role - we understand that and, you know, both Cath and I have been there - but it's a bigger issue than simply how to do we deal with a whole lot of family members who are providing direct care and support. It's about assisting families and supporting those families who have - assisting families to build those networks and supporting those who have. The other point around this sort of - I guess this target group issue is that it necessarily follows that at least some people with a label of severe or profound disability will have a decision-making disability. So the whole question of substitute decision-making must be taken into account at a number of levels, both in decision-making, including people aspects of service and so forth.

Moving on to that question of who makes decisions, certainly as I take the previous participants' comments around individualised funding, we would certainly support the concept and practice of that and we're concerned with moves, certainly in Queensland to wind that back. We'd like to make the point that individualised funding doesn't mean you just hand over a whole lot of money and it's not accountable. We note the points about accountability in the issues paper but there are many examples of families and individuals having that decision-making power over funding and remaining accountable for its use.

For example, at Mamre Association, not the Pave the Way project but in the sort of direct service part of Mamre, Mamre supports around 200 families. It's a family support organisation. At the moment 165 of those are receiving what we term as cash payments. It's sort of what we term as family-managed funds. So the amount of funding that goes to them could be through an individualised amount from a funding agency or it could be an allocated amount from some block funding that Mamre makes a decision about with the family to allocate a certain amount. The families get that cash, but it's accountable. Every month they have to send in receipts and so forth and, unless that's all accounted for, the next month's payment will be delayed. At any time the administration can check on things. There have been very, very few examples - I think only one family who actually didn't comply with that in a significant way. I might add that this is not just little bits of money. There are some people receiving over $100,000 and it's being handled this way.

In terms of decision-making, and Catherine will come on to talk a little bit more about the nature of the planning services that we would want to have included in the scheme - but planning obviously assists people to make decisions. So the idea of decision-making - it's not just about who makes the decision and so forth but it's about how can these decisions be made in the best possible way for the best possible outcomes for people with disability. It's also, we would believe - would support the funding being used efficiently. I mean if any of us do some planning and work out exactly what we want to do, we're much better at efficiently allocating the resources that we need to, to whatever that activity might be.

It's also the case that people with disability and families can have more decision-making power if they're supported in their planning, and that can include the development of support networks and what we talk about with families, support circles. These are groups intentionally created that can offer advice and assist with decision-making. So again, we'd want to see that sort of notion accepted and respected within any scheme. The notion of a supported network incidentally is accepted in Queensland legislation under our guardianship legislation, so it should also be possible to build that notion into any national scheme. So I'll just hand back to Catherine to talk briefly about - - -

MS RAJU (PTW): Just one last point about the Mamre experience with individualised funds and cash payments. When that was introduced with families it wasn't just a sudden decision and it's up to you to get involved in that. There was really quite considerable preparation with families and ongoing practical administrative support as well as other kinds of support to make it work. I think that's something that needs to underlie all of this as well, that when change happens to families there needs to be support - and individuals, there needs to be support for that change to be successful; set it up for success, not failure. There's lots of people with experience in how that can happen.

So I suppose looking at chapter 8, which is The Nature of Services - and there's certainly a list of core formal services that you talk about here for well-functioning disability care and support. But from our perspective we believe that succession-planning services like the ones that Pave the Way offer and other organisations like Parent to Parent in Queensland and other parts of Australia offer can play a really important part in this scheme, as Jeremy and I both alluded to before. Again, not planning that is attached to a service that a person is with. While that will be important to determine how that service works in the life of a person, this planning that we're talking about sits outside that. So it is with the family, with the other people that Jeremy mentioned in terms of the networks or more formalised circles of support. So people look at that overview and that long-term safeguarding kind of planning.

We're not aware of any project quite similar to Pave the Way outside

Queensland in this regard. In fact, we are often invited to conduct workshops in New South Wales, ACT, Victoria and Tasmania where we have been to do this work, and also New Zealand, for that matter. It is something that people are attracted to because of the nature of the kind of planning that we talk about: outside service planning driven by families across whole levels of planning, looking at the notion of how to invite others to be part of that.

One of the big issues that we face, and other organisations in Queensland like Parent to Parent, is how to do this in regional and remote areas of Queensland. That is a struggle for any service that works Queensland-wide and it would be the case in other states of Australia as well. It is something that really needs to be thought through in terms of all of this quality of service delivery but also from this planning perspective, how that is best met.

I think in terms of the kinds of services that are talked about in the document, from our perspective planning with families - I think what we've learnt and what we know as family members ourselves is that you can't presume that the status quo is what people really want in the end. Sometimes in our conversations with families it might start with a question about, "I'm looking for a particular day service or accommodation support service." When you get involved in the longer conversation about the individual and the family and what their hopes and dreams or their particular individual gifts might be, the search at the end of that conversation is quite a different one.

I think that points to the value of two things that we've talked about: the underlying philosophy and vision and the need for planning, directing the kind of services that people may chose to use with their money rather than simply having a list of standard services that people can attach themselves to. So I suppose in that regard it would be an encouragement not to invest this money in capital building projects only which cannot be dismantled, if the money has all gone into that, but to look at a range of options, a range of things that people might want, not limited to current understanding about things but to start from the person perspective; that's what I mean.

I suppose just moving on to that also with chapter 9, How Much is Needed, again I think our perspective and our take on this is the importance of planning, because really without planning at an individual level it's actually difficult to understand what the unmet need is. Our perspective also with planning is that planning doesn't just happen once, it's not, "Let's do a plan," that exists on a piece of paper once and forever, but with ongoing planning through the stages of a person life it actually can become apparent that there may be sometimes even less need for support. In the example of perhaps a whole lot of support needed at particular life transitions, when someone is moving out of home into their own place, a lot of support may well be needed. When that's in place, with other people around them, maybe that kind of support changes, if not decreases, but of course there will also be the case where it will increase as people's life stages go on. So planning is not a noun, actually like it's a verb and it's an ongoing process.

So Jeremy would just like to talk briefly about our last point in the paper. Did you want to add any more to that?

MR WARD (PTW):   No. Just finally and very briefly, as I know we've run out of time I think, in terms of the financing options we just wanted to encourage the commission to look at what taxation reform might be useful. One pretty obvious one for us as we talk to families is many families who have the financial capacity, and obviously that varies, but those who do will be providing financial support in all sorts of different ways to their family members; it could be in actually paying for direct paid support or it could be paying for pieces of equipment. It's often certainly under the equipment scheme in Queensland, it's been the case for many years that often families or the individual have to supplement what was provided.

Now, if those sorts of contributions were to be tax deductible it would make it much easier for more families to provide that support, and for those families who do to provide perhaps more. Indeed if the tax deductibility was attached to the individual in need rather than the family or the parent, then there could even be wider group of people who could provide financial support; so extended family, grandparents obviously often support grandchildren. I even know of examples where close family friends have provided regular payments. They might have paid for one night of support, for example, to assist someone to be living in their own home. So if all of those could be tax deductible, that would become a much more attractive way of families, and the community indeed, assisting in the financial support.

Of course there could be other ones too in terms of the Special Disability Trust. Even though there have been some improvements from the original design of that scheme, there are still issues around capital gains tax there, for example. So we just encourage the commission to look further at those ideas and we can spell them out a little bit more when we do put in a written submission. That's all, I think, isn't it, Catherine?

MS RAJU (PTW):   Yes, that's fine. Thank you.

MS SCOTT: Well, thank you very much. I'm sure we'll have questions now about all sorts of topics. I've got a few in my mind but, John, do you want to lead off?

MR WALSH: Yes. I've got a couple, Patricia, but I'll just ask one every round if you like. My first question, really, to you, Catherine, about your very first point around philosophy. I'm very interested in that and a lot of people have mentioned that to us. What I'd like to explore is something for us as a group of commissioners to recommend (indistinct) in the long term and I'm just wondering whether you've given any thought to an institutional or governance framework which would have philosophy or a vision as part of its terms of reference?

MS SCOTT: John, you might just have to go to the core of your question again; we just had a little bit of noise in the background and it cut out some of your words. We got most of it but not all of it.

MR WALSH: Yes. My question is, have you given any thought to the governance or institutional framework which would sustain a philosophy or a vision for the whole system?

MS RAJU (PTW): Yes. We were talking about that briefly this morning, trying to work out what this would look like in practice, really, but I imagine that it would be involving people from the broader community in that discussion about what that might look like. I'm not sure in your actual service design where that would really fit but it would need to be something over and above the actual running-out of the parts of the model that you describe in the paper. Jeremy, did you - - -

MR WARD (PTW): Yes. I mean, I suppose I would be quite attracted to the idea of some sort of statutory authority - if that's what you're talking about, the overall governance.

MS RAJU (PTW): Yes.

MR WARD (PTW): I mean, obviously there are issues whichever way you go but one of the problems with government agencies that everyone has experienced everywhere, I'm sure, and that is the often high turnover of staff, the short corporate memory. I mean, you feel as if you're having to say the same thing again to a whole new lot of people five years down the track. So it's possible, I think, to build - especially something of this size where you could have decent sort of career paths for people and so forth, and if that agency was then set up with a very strong vision and set of values and principles, and included really good involvement of people with disabilities and families, either directly or in really sound advisory mechanisms and so forth, then I think that could go some way to dealing with this issue. Beyond that we really haven't been able to give it terribly much more thought at the moment.

MR WALSH: That's good, that answers my question.

MR KALISCH: Perhaps just following up John's question a little bit. I suppose most schemes when they're introduced and particularly if they've got a legislative basis, the legislation introducing the particular scheme will have an objective or a purpose. I mean, is that partly what you're getting at here as well as the structures that John was talking about in terms of consultation and engagement?

MS RAJU (PTW): Yes. I think it would be setting the framework of thinking about it, I suppose, if you like, from that philosophical level so that it's not just meeting the needs of people with disability but what are those needs likely to be, what can they aim towards in terms of the kind of life that a person with a disability can lead. So it's sort of setting the framework for that kind of thinking, not just on a pragmatic level but on what you're aiming for in terms of the quality of life and the possibility. Is that what you mean?

MR KALISCH: I suppose I'd sort of just give it back to you as well in terms of your submission and any further documentation you provide to us to actually think about - - -

MS RAJU (PTW): What that might look like, yes.

MR KALISCH: - - - what you think might be the purpose for any scheme; not necessarily passing - - -

MS RAJU (PTW): Yes.

MR WARD (PTW): If I can just say I think if you go from the individual to everyone, we talk about, families talk about people having a good life. It's ordinary language. Why wouldn't a scheme like this have as its fundamental aim and purpose supporting people with disability to have a good life? Now, if you look at what you think is a good life and what everyone in this room thinks is a good life, I would say that a whole lot of things that happen in the disability sector wouldn't be included. Just choosing where you live and who you live with, for starters.

MS RAJU (PTW): So that then filters down into all the other bits that the scheme could do, as we said in service design and service delivery and all the rest of it.

MR KALISCH: Thank you.

MS SCOTT: Certainly, Jeremy, some of the schemes we've spoken to that exist in Australia now have to have some sort of benchmark and your benchmark is "a good life" - an ordinary Australian might call "a good life". Other schemes have described it as "what is reasonable". I guess at some point you need some sort of benchmark and you're nominating one in "good life". Can I turn to the issue of individualised packages and choice and flexibility and accountability. You want the flexibility in this scheme that a family or a circle of care, if they saw fit, could use some of the package to undertake planning, to think about transition points and ensuring that a support network exists into the future.

Would you want that to be nominated on a list or would you allow quite considerable freedom for the individual and the family around that individual to be able to work out what services they want to spend their money on, and how have you operated under your own arrangements in terms of flexibility and choice versus accreditation and accountability? Have I been clear?

MS RAJU (PTW): Partly, I think. So first of all you're talking about - - -

MS SCOTT: In some places individualised care comes with a list. You can use the money but only for these purposes.

MS RAJU (PTW): Okay, yes.

MS SCOTT: I think you've suggested to us that make sure what's on the list also includes succession planning or planning arrangements. So that you might just be after us including the word "planning" or you - - -

MS RAJU (PTW): As one of the core services that you're talking - - -

MS SCOTT: As one of the core - or you might be saying to us, "Give people flexibility," and if it's planning for Jeremy, it might be a writing course for you, Catherine. So do you know what I mean? Don't go to the extreme of - - -

MR WARD (PTW): Too prescriptive.

MS SCOTT: - - - too much prescription.

MS RAJU (PTW): Yes.

MS SCOTT: I just want to check what's your experience with flexibility versus accreditation and lists and so on. Where do you fall on that issue?

MR WARD (PTW): Do you want me to have a go?

MS RAJU (PTW): Yes.

MR WARD (PTW): For starters I think what we're saying about the inclusion of planning services, for want of a better term, in the scheme can happen differently than coming out of people's individualised funding. So, for example, the scheme might simply fund projects, organisations, in different parts of Australia, as we are. We're funded by disability services. We don't take money from families - occasionally we do for live-in workshops - but we're funded by government to do this work in Queensland, so irrespective of whether families who come to us have any individualised funding or any funding - in fact most of them don't have anything. So that's one point.

In terms of the accountability question, I think if I hear what you're saying that the struggle has - accountability is fine and certainly Mamre, for example, has to go through all of that and so on and that's never really been an issue. They have just gone through another audit and came out very well. The question is more if you have a set of values or principles and it could underpin this scheme, such as everybody has a good life, or that's the vision, what happens if someone comes along and says, "We've done a lot of thinking about this and our vision is quite different from that in fact. We want segregated accommodation and dah dah dah dah dah," and that's what they think is for their purpose.

The challenge certainly, again just taking Mamre as an example, has been not to say to families, "Well, we're not going to work with you," but to keep on having a conversation and showing people examples and so forth of what alternatives are available. Now, that may not quite answer your question but I suppose it's just an example of how you deal with those sorts of challenges. With individualised funding I'm not sure about having a list as such. I mean, if you've got a funding that's available to support someone, usually it's tied to accommodation, it might be employment, it might community access or something like that. We would argue that those distinctions really just put barriers up in front of people.

So as long as it's used to support the individual with the disability in meeting their needs - if one need is to do a writing course and one need is to do something else to follow their dreams, then why not, if they can't do it because they've got a disability without support. So it's not about, "I'd love to go and do a thousand-dollar workshop over that weekend with this guru" - and they might have to pay that - but the support money is to support them to get there and do it. Do you see the difference?

MS SCOTT: Yes.

MS RAJU (PTW):   So are you talking about this being a specific list of services that can only be accessed - - -

MS SCOTT: I guess we've heard all sorts of ideas. We've been to other places and we've got about 85 submissions now. We've got great diversity of views. Some people say, "If a package is $5000, just have the lightest touch on accountability." You'll have that planning process at the start and you'll say, "Well, speech therapy looks like it would be ideal," but if the individual then decides that "that speech therapy is not for me" or the family doesn't think that's a very sensible approach but something else is, they should have some degree of freedom to move the money around and spend it as they consider fit and - - -

MR WARD (PTW):   Yes.

MS SCOTT: - - - that's the idea. Other people say, "But what happens if the family considers that stem cell treatment in China is the best use of the money," or that "dolphin therapy is the best use of the money?" So you end up with this diversity of views about the level of appropriate flexibility versus - you can go overboard in accreditation and overboard in acquittal, and on the other hand it can be so flexible that people wonder whether that was necessarily a very good use of the funds. So I guess because you've had experience in exposure to these issues I'm interested in your wisdom on this topic.

MS RAJU (PTW): Yes.

MR WARD (PTW): We haven't been directly involved with the direct service side of Mamre but I guess we've both been involved in teams that have discussed it over the years, and from my perspective often it's an ongoing conversation with people. So, for example, under a family support program that the state government has been running here for quite a few years there's a lot of flexibility allowed for families and so they might come and say they wanted to spend $10,000 on a swimming pool. Now, if that's clearly for the use and benefit of the individual and it's one way they can get really good exercise, et cetera, et cetera, that's fine, but if on a closer examination it looks as if they will hardly ever use it and it's really just for the family, well, you know - and so a lot of that, I think, can't be dealt with just as strict criterion. The business about stem cell treatment in China, I mean, I don't see why you couldn't insist that if money was going to be used for medical reasons that there had to be specialist opinions supporting it, et cetera, et cetera.

MS RAJU (PTW): So perhaps individual responses to that rather than - - -

MR WARD (PTW): Yes.

MS RAJU (PTW): Once you start to try and tie it all up it becomes impossible.

MS SCOTT: Yes, that's right.

MS RAJU (PTW): I suppose our lived experience is that that can work, and that was your question.

MS SCOTT: Yes. I think that's right. The message I've got from both of you now is that don't be overly prescriptive in our advice to the government on this topic but suggest that conversations themselves can be the mechanism for ensuring some gentle guidance.

MS RAJU (PTW): That then goes back to the whole thing about what sort of services you get doing this work, which goes back to the philosophy and the principle, et cetera, et cetera, so it all ties together in the end.

MR KALISCH: So tie it to the objectives but also have this in the back of your mind when the planning process is running out.

MR WARD (PTW): Yes.

MS RAJU (PTW): Yes.

MS SCOTT: John, I should now give you a chance to ask your second question.

MR WALSH: Thank you. Catherine and Jeremy, you've talked a lot about planning and inclusion and participation and when the person with the disability has a group of friends around them or a group of people around them. My question is, how successful have you been and your experience in actually finding those group of supports? So I guess what I'm asking is, what does the future workforce look like, whether it's voluntary or partly paid or totally paid; and where does it come from? Is it young people, is it old people, is it university students; how do they get motivated to participate in this sector?

MS RAJU (PTW): I suppose there's two things there, I think. The first is when we talk about families involving other people in their thinking and planning, then that is not the workforce side of your question but that is really beginning with that first question of inviting other people, as we call it, whether it is through a network or circle, or whether it is just a conversation with one other person through an informal planning and then other people become involved. Of course we will often meet people who say, "I have nobody." Through conversation sometimes there may be just that one other person, which is enough to begin that process of thinking that way so that in the end there is at least one other person who's bearing that person with the disability in mind at some point. So that's, I suppose, one part of it.

The workforce thing is an ongoing question, I think, for all services that are involved in this area. I think at Mamre at the moment, on the other side at Mamre which does deal with support workers and things, is quite well off in that regard and part of that, I think, is the support that is given to workers in their work because it can be quite isolating, especially when you get into individualised funding where people are not working in a larger service but might be supporting a person individually. So those support workers themselves need support of an organisation that values them and that provides them opportunity for professional development, for good levels of pay, for being part of a service that has a positive direction so that they feel they are contributing. This sounds a bit vague but I think these are the things that workers say when they will come to work there, that that's what attracts them.

Certainly there's a lot of families who use university students, I suppose for one reason that they're looking for work but secondly they can be young people who are actively engaged in positive lives, I suppose, and know how to live that because they live it themselves. We find many families in Mamre who will keep a worker, to use that terminology, right through the person's university degree, so that can be four, five or six years, and relationships are built in that way which are often then ongoing outside the paid workforce, and I think that's a reflection of the positive nature of the work, really. So I suppose that's some of our experience.

MR WARD (PTW): Yes. Just to follow up briefly; one of the difficulties, and I would agree too and certainly in my experience, certainly in our family, we always avoided people who were trained because we thought they had to be trained to support our daughter and you wouldn't get that at a TAFE course. We wanted people to be bright, intelligent, good basic values and we want them to be committed to that particular role, if you like, that work role. The difficulty in finding those people in regional Queensland is huge. So as we travel around Queensland it's all very well for us to say in Brisbane, "Well, there are all these students around;" half those students come from regional Queensland. So it's a huge problem but, I mean, I guess what we encourage people to do is, "Don't worry that there aren't any people around in your community who may be trained. Look for people who have the values you want, who have the - and if it requires some lifting, obviously who are strong," and so on. By developing the networks you're more likely to find those people by word of mouth.

MS SCOTT: Can I just explore a little bit further on this, and at the risk of we're going to probably reduce the time we have for lunch now but that's okay. Some people have presented to us and have said, apart from the parents, there's almost no-one that they really can rely on; that their circle has become so small over the years; that people give up work; over time they give up other things that would have kept them engaged with the community; that it becomes extremely isolating and they fear that with their own death that their dependent child will struggle to have any sort of real contact. Now, there must be cases, I am sure, where you must encounter people who don't really have a large, extended group to rely on; they might not belong to a church, may not belong to a social club. Have you ever had that case and then were you able to resolve it to find other people who were prepared to take on what could be a quite considerable, I suppose I'd call a moral responsibility, even if it's not a daily caring activity?

MR WARD (PTW): Absolutely.

MS RAJU (PTW): I think that is the important distinction and I think it's sometimes on that level of conversation that you can begin to do that. This is even the case with families and siblings, which is one of the interesting areas of the work that we've found with families where so often there's a conversation where siblings -

it seems to be on either of the spectrum. Like, "This is your cross and you'll take it up;" or the other end where, "This has got nothing to do with you, it's not your burden." What we're finding in the conversations with brothers and sisters particularly is that very often they want to be part of the conversation but they don't know how to have that with the family, and it's through these planning conversations with these larger families sometimes or even smaller ones, that it's just having that first explicit conversation about what are the expectations, what are the hopes, what are the fears that that will start.

So people who will begin with us by saying, "There is nobody," there will often be people once it becomes clear what it is that you are asking. So that's why your distinction, I think, was very important, that it's not, "You're going to be the live-in carer for the rest of this person's life," but that moral responsibility or bearing them in mind or being part of that decision-making. I mean, as Jeremy said, we don't say to the families, "This is what you must do." That's not our work at all because wherever a person lives, the stuff that we talk about, having other people involved in your life, having your legal affairs in place, having some ongoing planning, is important wherever a person lives. So it's that sort of - - -

MS SCOTT: That's very encouraging. Have you encountered cases where genuinely people couldn't think of an extended person?

MS RAJU (PTW): Yes.

MR WARD (PTW): Yes.

MS RAJU (PTW): Certainly older families for whom this has been, as you said, an ongoing and increasingly isolated life all the way, really.

MS SCOTT: Look, not for now but maybe when we get your written submission we'd certainly welcome - in all our reports - just as in normal behaviour, the use of examples - - -

MS RAJU (PTW): Stories.

MS SCOTT: - - - and stories can be very revealing. I guess we'd be interested in learning a little bit more about especially those difficult cases where people might be in the 80s and 90s and how do you then handle the situation.

MS RAJU (PTW): Certainly. Just to say that there isn't a place for paid services in all of that either, that's sort of what I meant.

MS SCOTT: Okay.

MR KALISCH: Probably the other thing I'd encourage you to think about, obviously we're talking about some really good examples where families support, encourage, try and discover the values and the aspirations of the person with the disability, but I'm just wondering where that isn't the case as well, where there might actually be some families moving down one road and the person with the disability having quite different perspectives.

MS RAJU (PTW): Yes.

MR WARD (PTW): Absolutely.

MR KALISCH: How do you actually deal with that situation in your environment?

MR WARD (PTW): Well, is that a question?

MR KALISCH: Well, perhaps something for you to do with the submission.

MR WARD (PTW): Yes, we can deal with that.

MS RAJU (PTW): Certainly. So there is just some material here if you wanted to read a bit more.

MS SCOTT: Thank you.

MS RAJU (PTW): In terms of stories there are some on our web site that are from families.

MS SCOTT: John, shall we wrap up now?

MR WALSH: Yes. Thanks, Patricia. Just in ending, another thing I'd like you to do in your submission maybe is - really, I think, what Pave the Way seems to be doing is running a very personalised and sensitive planning and coordination facility, but which is very different from what traditional service provision is where you have a coordinator that effectively says, "Okay, that person is going there," and it's a very de-personalised "get what you get" sort of thing. I'd be interested in the - I guess the burden of your - what does it cost to provide that sort of service. If you were a scaled part of the system, Pave the Way type model part of the system, what would it look like and what would it cost.

MS RAJU (PTW): Thank you, John.

MS SCOTT: Sorry about setting you homework.

MR WARD (PTW): It's good to have some focus.

MS SCOTT: Thank you very much. We now call to the table Ian and Heather Alcorn. Well, good morning, Ian.

MR ALCORN: Good morning, everybody. My name is Ian Alcorn and firstly apologies for Heather who couldn't come at the last moment. Just listening to some previous discussions I'm a little bit concerned that my topics may not directly relate to the terms of reference but if you think that they're a little bit out, then I'll be happy to be told to get on my bike and go elsewhere. I have put in a written submission about two topics that I get quite excited about from time to time and they are the lack of suitable residential options for people with a disability and also the complexity of Centrelink correspondence; I guess there's two things.

Just to give you a bit of background of where I'm coming from, I guess I'm representing my daughter Robyn and that's why I take every opportunity to advocate for her and her friends, so I'll go to any forum that I can do to do that. She's 26 now, as I might have said, and she lives at home with us. I guess she falls into the range of having a mild to moderate intellectual disability, is on the disability support pension and is a part-time permanent employee of an Australian disability enterprise. She works four days a week. She's quite independent in a lot of respects. In other words, she goes to work on public transport to and from and socialises with her subculture of friends.

However, having said all of that, she still needs quite a deal of support in avenues where decision-making is required and needs day-to-day types of support in what she does. My wife and I have both now retired. We have a history of working in education and with students with special needs. I'm also involved in the Australian disability enterprise where Robyn works, on the management committee, so I try to be informed about things that are available for her and her friends. So that leads me to my two topics that I want to talk about, if that's okay.

MS SCOTT: Yes.

MR ALCORN: The first one about the lack of suitable residential options available to people with disabilities and, again, I'm biased towards my own family in that respect in that I guess I'm more concerned about her future. In the south side of Brisbane I don't consider that there are any suitable options for adults as Robyn my daughter and many of her friends. If there are, we're really not made aware of them. There seems to be options for people at the ends of the spectrum. In other words, those who have high needs and are perhaps in care of the disability services, or perhaps it goes to the other extreme where people are, I suppose, planted in certain flats or units or places and supposedly have some type of care, but there doesn't seem to be any range in the middle.

I would think that many of the people of Robyn's ilk need somewhere in between where they can have an independent type of lifestyle yet they can have the support that they need on a daily or very frequent, 24-hour basis. They need an environment or they need a way that they feel safe, they need support and that they feel supervised and that they're with their friends. We seem to have gone down the road when we're talking about aged care people where we have tri-levels of care and where we have higher needs, we have middle, we have those that are independent, but we don't seem to have addressed that in terms of people with disability at all. In some ways people like my daughter at this stage could live in a very independent situation yet within a situation where there is that type of care or support available when she needs it.

They also need to be very close to public transport and that concerns me sometimes when people are implanted in flats or things so they're nowhere near public transport or near shopping centres where they can go and do those things if they're capable of doing it. The other thing is they probably should have the option of being able to rent those or buy them. In other words, they could own them or at a low rent as is available to other members in our community who are of low income. I guess I am aware that certain parts of accommodation are a state government responsibility and that I guess if there was an urgent situation then somehow my daughter would be accommodated, but I'm not sure that the option that was provided would be what I would want her to have, or whether she would want to have it.

These kind of concerns have been expressed by a number of people and I know a number of the families that are Robyn's friends over the years but we don't ever seem to see any actions. So I guess my plea to you and to part of this commission is to try to encourage levels of government to explore and actually provide, maybe in cooperation - and I would think in cooperation with private organisations or non-profit organisations, additional forms of residential accommodation for these students. I guess it's as simple as that. We heard from Mamre before about planning for people and things like that. It's very difficult to plan when you've got no options. That's the point I guess I'm making. At the moment I don't know of any options.

I haven't got any great solutions apart from the fact that Youngcare - and I notice Youngcare is coming in to talk later on. There are slightly different needs between, I gather, some of the people that are being catered for; Youngcare and the type of people that I'm talking about, my daughter. I'm also aware of the term called "sheltered housing" in the UK where I guess it's very similar to what our term was called "sheltered workshops", which was before the Australian Disability Enterprises, and I guess that's the broad type of concept that I'm talking about. So that's all I really wanted to say in terms of the accommodation. Would I move on to the next bit or would you - - -

MS SCOTT: I wonder whether we should pause there and just ask a few questions, Ian, and just see how we go. It seems to be like accommodation is a really hot topic and people have got very diverse views. You're close to the action so you're the person to ask. It seems to be often the concern is about turning accommodation back into institutions. Now, maybe you don't have that concern, but what's the sort of - do you have in your mind the right number? We were told yesterday very emphatically by an academic that it was outrageous to think that 30 people could be together and you wouldn't end up with a harmful institution. So do you have a view on this? You've worked on - - -

MR ALCORN: Yes, I do have a view and I see a very simple solution to it in fact in terms of the Department of Housing in Brisbane and around the suburbs where I live are building small complexes of units. I think they're six to eight complexes of units where people buy into them or either have low rent, but if one of those units was reserved or a person was residented there and was afforded low rent or whatever have you to look after those people, I think that would be an ideal. I don't prescribe to large numbers. I don't think 30 - I wouldn't go that far. I think that if you had a small group, why not? They have their own subculture. This is the part that people - they all know each other, these adults. They meet each other through Brisbane, they socialise, some of them work together, they go to the Broncos together. Not that I think it would be good that they live together and work together and all do that together, but they're aware of each other's needs and they look after each other. They need somebody there to say, "My go kart's run out of money. What should I do?" or, "Should I buy this?" or, "What is that going to cost?" So that's what I'm talking about.

MS SCOTT: Good. Thank you. Now, John, do you want to ask a question or shall we move on to Centrelink letters?

MR WALSH: No, I think that's great. I guess my question, Ian, is just extending a little bit. I mean, you talked about eight units and a person with subsidised accommodation just to effectively be the go-to person for those people. What if those eight units were in a larger block sort of, if you like, spread among people without disabilities? Could that be an equally - - -

MR ALCORN: That would be even better still. No, I don't have any problems with that as long as - I think that would be ideal. I just think that as long as those people knew that they had someone there all the time and that they felt secure in that they felt safe and they felt supported in that complex, that would be good.

MR WALSH: Yes.

MR KALISCH: Just one question following that up a little bit. Obviously the provision of support and providing that opportunity for people to rely on someone else or draw on that support is quite critical. Could you imagine a situation where that person wasn't resident in situ but was, say, nearby or they're aware there was a service that could provide that support? In some cases where - - -

MR ALCORN: Yes, and that's the model that happens a lot and that's the model that concerns me at the moment, that those people aren't there when they're needed. I've seen some young adults become very vulnerable to a lot of outside - well, the guy that turns up to sign them up to the FOXTEL agreement and they sign up on the maximum amount, and the contract is signed because they didn't have anybody to talk to at that stage and they're basically bullied into doing something like that, and that's just one instance, or you haven't got any food in the fridge, it's time to go and get something. So I think it's important that the person is on site. The other problem, and we spoke about it before, is that in the present model at times those carers who come in so many times a week change so frequently they get to know the person probably for a few months, the trust is there and then it's gone. So that's why I would be much in favour of a live-in person that's there.

MS SCOTT: Thank you. Just while we're on that person, other people have raised this issue. Does the person need to have a certificate IV, do they need to have certain values? What's the - - -

MR ALCORN: I think Jeremy made the point before that maybe it's the person's philosophy on life that's important and the fact that you can care and that you're a practical person more so than having three university degrees.

MS SCOTT: Thanks for that. That was very clear. Now, on to Centrelink.

MR ALCORN: Now, my other little hobbyhorse, and I won't keep you too long on this, is Centrelink forms. Anyone who's got people with a disability will realise that there is a requirement to fill in forms and there is a requirement to update information with Centrelink and I suppose at the beginning I shouldn't be too harsh on them because they do provide benefits to us and to people which we should be thankful for. However, having said that, I can get quite critical of the forms and the complexity that they send to the person with disability or they send to the carer or the nominee.

The first concern that I have is, it seems to be that the forms refer to a generic type of person with a disability. In other words, the forms seem to take no account whether or not the person has got a back injury and has a university level of literacy and numeracy, or whether the person is like my daughter who can read a few words but not understand very much at all and I have to fill it in, or to a person who's got quite severe intellectual disabilities and who can't read anything. We're all given the same form and we're all expected to fill it in regardless, and we get six or seven pages of introduction as to why we should fill it in and why we shouldn't fill it in. So I guess one of my suggestions, and I don't know how practical it is - I know it would be difficult to do, it would be lovely if everybody got their own individualised form - but I would be pleased if Centrelink could perhaps give some consideration to recognise that there are different forms of disability.

There are different abilities within the word "disability". Some people have good numeracy and literacy skills and some people have none, but we're all treated the same. For carers, sometimes us, sometimes we hate filling in the forms and sometimes I do not understand what they're talking about. I know at where Robyn works when some of these forms come in, the staff have an inordinate number of requests to help people fill in these forms. So I guess the thing is really, there is a concern about the way the forms are designed and the level of literacy and numeracy that person has. Centrelink know that; Centrelink know whether you've got a physical disability or whether you've got a major intellectual disability. So I leave it at that.

I want to just refer to a really good example of this, and for those of you who have a child with a disability you'll know sometimes you get the review of mobility allowance form, which comes out, I think, once or twice a year and we've just had it. It's about seven pages long, however only one page refers to my daughter. So I have to go through eight pages of it to fill in the one page that refers to Robyn. I'd filled it in this year, sent it off and about two weeks later I got the form again. I rang up and said, "Look, I've already filled it in." She said, "We've got no record of it. You'll have to fill it in again," which I said a few words and I said, "I'm not going to do that." However, that afternoon I got a letter in the mail saying, "Your review of mobility allowance has been accepted." That's a different issue.

I guess what I want to say is that Centrelink have and know all the information that I am putting into that form. They already have it because they give to me a rate of payment every three months which knows where my daughter works, they know how many hours she works, they know her wages, they know all that information. It's just that their databases don't talk to each other. So all they really need to do instead of sending us eight pages - and I don't know how many copies they send through Australia of eight pages that we only have one to fill in - all they need to do is to have their data talk to each other, give us a form to say, "Is this still correct? If it is 'Yes', tick it and send it back," and it could be as simple as that. I know they need to do it, I know they have to do it, but it could be far simpler, it could be a lot more streamlined than that.

I talked about the language - well, for instance, the whole last page of the mobility allowance talks about the Privacy Act. Have you ever tried to explain that to a person with disabilities? I know I'd sat down with Robyn and said what that meant and she'd say, "Yes, dad. Yes, that's - understand," but she doesn't really understand all of that. Is that necessary? It probably is necessary under legislation but I think we've gone a little bit too far when we're sending that kind of stuff to people with moderate intellectual disabilities.

I'll finish up just one thing. I've tried to raise this point with Centrelink several times. My letters always get lost. I don't expect to have an instantaneous response. I don't expect that all of my suggestions will be taken into account. I know the systems. I've worked in systems before. I know how long it takes systems to act and do that. All I expect is that I am given a sensible written reply with some form of courtesy that some of my suggestions might make some sense. However, I haven't had a - I wrote two years ago about this. I have not had a written reply from Centrelink. I wrote to the Centrelink customer service relationship service to complain that I hadn't got a reply. I did not even get a reply from them.

So I'm just concerned that if I'm supposedly an able bodied person who has the time now to sit down and do this, what happens to people who have a disability that try to suggest these things? Are they ignored? Is it too hard or just, "It's too difficult, so go away and we'll forget about it"? I'll stop there. So my plea to you through this forum is I guess I would like the people who design forms in Centrelink and who want the information to really consider what they want and really talk to the people who have to fill them in and who are supposedly having to read them. I'll stop there.

MS SCOTT: Well, any questions on that, John, David?

MR WALSH: I don't have any questions on that.

MS SCOTT: I think that's possibly your sympathetic tone. All right. Thank you very much, Ian.

MR ALCORN: Thank you.

MS SCOTT: Cyril and Patricia Dennison. Welcome, Cyril. For the record, could you just indicate your full name and whether you're representing yourself or an organisation, please.

MR DENNISON: My name is Cyril Dennison and it's really a submission from myself, also representing my daughter Michelle, who has an acquired brain injury. My wife Patricia apologises, she can't be here. A carer phoned in unable to care for the daughter, so my wife is at home. I tendered a submission to the commission about a fortnight ago, so I daresay you've had time to browse through it. My submission is slightly different to others that I've heard, in that I've directed the bulk of it to this no-fault social insurance scheme that is under consideration.

While I totally agree with the concept, my submission is pointed at areas that you should be aware of, because in the State of Victoria the Transport Accident Commission has this particular policy and it has failed my daughter and our family in a big way; it has been very expensive. So if I can just refer to my submission and read it to you, if you don't mind, and it will give the audience here a better idea. It's without prejudice.

The experience and the knowledge that I bring to the inquiry is as a parent and father who with his wife and partner successfully raised a family of three, two of them having gone to live productive and happy lives as citizens in the Australian community. I also bring to the commission my knowledge and point of view as an individual, an Australian citizen, from experiences that I have in taking care of my youngest daughter, who is now 36, 24 hours a day seven days a week, as a consequence of an horrific accident in the State of Victoria on 7 October 1996. She was the 100 per cent innocent party.

I have also given the commission a copy of the court order and her medical assessment, for your records only. But I gave them to you so you could see how badly injured she was. She is what would be described as a highly-dependent person. The court order, that's something else as well. As I have pointed out previously, the intention was to address this no-fault social insurance situation, something that you're contemplating.

While this would be a worthwhile and admirable achievement, unfortunately, while the intentions of a no-fault type legislation may sound good, practice and application would be fraught with restriction and legal dangers to personal freedoms of all or most Australians under common law if the commission were to consider the legislative model from the Transport Accident Commission of Victoria. That is not to say that a just and reasonable outcome could not be achieved. It will have to be achieved without detriment to the responsibilities, freedoms and entitlements of every Australian citizen that we are guaranteed under our present constitution and common law, and even then we are not fully protected by common law.

Under the legislation of the State of Victoria the writer - that's myself - alleges that the legislation, specifically section 60 of the Transport Accident Commission Act, is corrupt, fraudulent and discriminates and that detains and conscripts - in other words, a Cornelia Rau factor - a parent or parents to supply the assessed uncompensated care that would have applied in the common law damages. So in other words, in the State of Victoria that particular piece of legislation states that the insurance company will only compensate 40 hours a week, that's it.

So in the case of my daughter - she was assessed as requiring 96 hours per week - who is going to supply it? The insurance company are not going to pay for it. Centrelink are not going to pay for it. It then comes to the family. The legislation there says that - and it's no-fault legislation - you, Mr Dennison, are going to have to look after your daughter 56 hours per week unpaid compensation plus all the other hours as well.

So what I am trying to do is alert the Productivity Commission and people like yourselves who may not be aware of the no-fault legislation in the State of Victoria that we don't need it nationally. If we're going to have no-fault legislation, that's fine, but you don't put a time limit on the amount of care that's going to be compensated. This is really directed at insurance companies, not at the general population who may be entitled to care. It's so, as I have mentioned in my submission further through, that the insurance industry carry their weight of looking after damaged persons.

My daughter was assessed as requiring 96 hours per week paid care. The TAC act was fixed to 40 hours per week. So when the QC for my daughter asked the QC for the defendant, "Who will look after the plaintiff for the 56 hours uncompensated care?" the response was that the legislation in the State of Victoria expects Mr Dennison to continue to look after his daughter as he has in the past. That's not on. I mean, I'll look after my daughter, but I'll do it because I love my daughter, and I have time and commitment to do it.

The other problem too that we found was that when my daughter had the accident and they took her into the intensive car unit at the Alfred Hospital in Melbourne, three metres from the door going into the intensive care unit you had staff sitting there from the Transport Accident Commission wanting the details and wanting you to authorise that - the Transport Accident Commission insurance it is, will take over the costs of the hospitalisation and what have you.

At no time were we made aware that Medicare looked after that anyway, under the HIC act or the medical legislation, which should have happened if they were going to try and direct it, you know, that they were going to pay their costs, they should have made us aware that this was happening, that by legislation and the constitution you're entitled to have those costs attended to under Medicare. So there are areas of conduct which need to be looked into.

Common law provides that a CTP insurer of a vehicle at fault who has admitted liability meets all the injury costs. The TAC insurance, the CTP insurer for the State of Victoria, had no vehicle involved in the accident, therefore had no legal or no common law interests in that accident, should have not been involved in any part of the damages settlement or the hospital situation. So what does the TAC act, section 60 do?

The construction denies the course of natural justice, the construction denies the course of common law with intent. It interferes or interfered with the Medicare HIC rights of Australian citizens under Medicare. It defrauds the party injury, party of entitlement, to full compensation. It forces the time and cost of uncompensated care on to the parent. So in our case it was a phenomenal sum of money that would have been paid to my daughter she didn't get.

Also, by the reduced compensation, it prejudiced the rights of the recipient to equal standing under the Social Security Act 1991, the preclusion period. I could go into detail later on, if you want. The TAC act, the Cornelia Rau factor, which I mentioned, it detains and conscripts and subjugates parents or spouse to the assessed, uncompensated care over the years to the injured person. This detention prevents the parent or parents seeking and obtaining gainful employment suited to their qualifications and experience; to earn, save and accrue assets for their future and retirement.

In our democracy, an Australian citizen would normally have to commit crime, be found guilty in a court of law before being gaoled - that is detained and restricted from earning an income. So it's bad legislation. People volunteer their services because of love, commitment and time availability. They're not volunteered by the state for the state's purposes because of bad legislation.

What I'm saying and pointing out to this commission is that if you're going to have this no-fault social justice insurance don't use the Victorian model. I mean, I fully agree with the idea that there are people out there who have severe disabilities that may have been involved in an accident or taken a drug overdose or stuff like that, fallen off a horse that need financial assistance and what have you, I fully agree with it. But there should be no time limit on the hours that they're going to get and it certainly shouldn't interfere with our lives legislation-wise, in other words, that we can go out and earn a living for ourselves and say, "Right, paid care can come in and do that."

I have had to look after my daughter the last 14 years. I've been sitting here listening to some other people and what they've said and I can relate exactly to what they're saying. You worry about what's going to happen to your daughter when you're not around and things like that. Before I move on the next section, is there anything that the commission wants to ask about that in particular or not?

MR KALISCH: I suppose just following up that question you posed to yourself, what happens when you and your wife are not around, what happens in terms of the care your daughter needs then?

MR DENNISON: This 40 hours that she has been paid is I've been working those hours but 10 hours a week, I'll get in a carer on Tuesday morning, a Friday morning and I'll have a break. I'll go and do whatever I want to do and we have a carer there on the Tuesday morning and Friday morning. So I've been saying, "Right, we're saving all this money against hired care, that goes for further down the track when I'm not around, she can then engage care." But that's not really the point. Where a person like this is involved in an accident or where public liability and stuff come into being, the insurance companies should be picking up the tabs and carrying their weight and the legislation should be there to make sure that that happens. So that all this services and what have you you want to supply the other market - sorry to put it in such a crude fashion, but you understand the point I'm making - goes to the people who need it and the insurance company should be carrying their part of the load.

MR KALISCH: So do you have an understanding that when you and your wife are no longer around that the TAC will then provide your daughter with financial assistance?

MR DENNISON: No, our case was settled. They shouldn't have been involved but they did, they paid a contribution to FAI who was around at that time. So all that's cut and dried. We've had to deal with what she was settled with which, incidentally, was about $1.45 million less than what she should have got, now all that would have been paid care. No, we've taken steps to put things in place and we're very fortunate that we have a close family and her older brother and sister will basically swing in and take over from when we fall off the perch or move on. We believe we have got a reasonable plan in place. But I'm more concerned about this legislation so that it doesn't happen that you follow the Victorian model and people become disadvantaged because of it because it's not only the person who is injured but it also filters down to the family situation as well.

MS SCOTT: John, do you wish to ask questions?

MR WALSH: No. Thank you, Cyril, it really just underlines the fact that building any scheme like this we need to be very careful about the design of it so that people might not be disadvantaged.

MS SCOTT: Please proceed.

MR DENNISON: So that was main part of the submission. So my recommendation to the Productivity Commission is not to use the TAC Act of the state of Victoria as a model for the proposed social insurance federal legislation for the reasons that I have previously put forward: that it obstructs and corrupts the course of natural justice and common law; it discriminates and penalises and it defrauds those who are entitled to substantial damages settlements from receiving same and it invokes the Cornelia Rau factor by the state; it detains, conscripts and places a burden of care of the claimant on the parents and spouse for the uncompensated care.

I have observations and suggestions and considerations: Commonwealth legislation, the preclusion period, that can be deceived by that Victorian act, and in fact it is, because when a person receives a substantial damages settlement they look at the total amount and they say, "Right, well, half of that we will expect will be income and you're not entitled to any social security benefits for whatever period." That's wrong because my daughter at the time of her accident was employed by the Attorney-General's Department, had a good job and everything like that and the solicitors work out what future pay she would have earned - you probably know all about that - and that was nowhere near the amount that the Social Security looked at. Social Security said, "Okay, she's going to earn $1.3 million in the future," when in point of fact it had worked out at about $600,000 and so they then say, "Righto, that amount of money, no, she's not entitled to it, and for the next 54 years she's not going to be entitled to a benefit." That's wrong.

My daughter was 22 years of age when she had the accident and that makes her 77. I'm 65, I'm entitled to claim whatever benefit - I don't know, I haven't claimed any. What I'm saying is that she's out of the system until she's 77. That's wrong and yet you have the stock market going into freefall and things like that. She has all of her money in there. She's lost umpteen hundreds of thousands of dollars, it's all going to come - in the end you've got a combination of bad legislation in Victoria plus what's recently happened on the share market and this is all going to come back on the Commonwealth government 10 or 15 years down the track to pick up.

So the preclusion period there, that legislation is wrong. I don't believe in that. There shouldn't be a preclusion period. Okay, she's not entitled to these services because she's had compensation but at some stage or other she might need some assistance and she should be entitled to it. The Medicare levy: you're talking about a way of financing this new thing. I totally agree with the suggestion that the Medicare levy should be increased by 0.8 per cent to finance it. I am in total agreement with it. The insurance industry contribution: I've made a suggestion here, particularly when we had a couple of previous people here having problems with accommodation and what have you. In our case we've already bought our daughter a house 10 years ago, it's a nice possie and it's gone up in value and that's fine. But every case is different.

So it's apparent that the principal beneficiaries of the new legislation will be the long-term ill, the disabled or those who are permanently disabled by accidents, sporting, workplace accident, drug overdose, self-inflicted or acquired, act of God or misadventure, criminal assault or the largest representation, motor vehicle accidents, that's where all your clientele are going to come from. Insurance companies like Suncorp, RACV and NRMA et cetera make hundreds of millions of dollars profit from motor vehicle and CTP insurance and therefore it is reasonable to expect a financial contribution from that industry by way of cash flow assistance in addition to the compensation that they have to pay these people. You will notice that mine is mainly directed at this because that's where my experience has been.

In the case of major insurance payouts for catastrophic and seriously damaged people, any major settlement over two million, the insurance companies should pay to the Commonwealth government $350,000 per person towards the cost of a large architect-designed, two-bedroom unit or townhouse and this would be put in a multi-purpose unit building for other persons of a similar situations conveniently located to all services. So that goes to the previous people here, that I'm suggesting that there be 10 of these type units, so 10 people, and that it have in it - with a two-bedroom villa, I'd call them, would enable a family member, a paid carer or a respite carer to stay or reside with the client when required.

A complex of 10 units would have one resident nurse on emergency call for all situations which means that a further $150,000 per person would be paid to a trust account. So when they settle a damages settlement 350 goes to the Commonwealth government to build a unit, and 150 into a kitty and the government would supply the carer to sort of oversight the 10 people in these units. Like my predecessor said here, they have their own subculture. They get to know each other. They feel secure in this little group and it would give a total security; they could overwatch the thing.

Now, what happens is there's a three-way input on this suggestion. The land is donated by the state. Now, for the people here in Queensland who would understand or recognise, I have suggested Brighton, near the new bridge down there. There's a great big swag of land down there which would be suitable for something like this. So the state donates the land, the buildings are financed by way of cash flow from the insurance companies and then the units are then purchased by the client on a damages settlement and they move in, so that they've got somewhere to stay and they're in close to all the facilities and what have you. When that person dies, because it's on Commonwealth land or state land, title of the unit then passes to the state. Then the next person who is damaged in an accident or something like that, they've got a place to go. They just refurbish and what have you but they've got a place to go.

At this point in time you're getting a lot of these seriously damaged people just winding up in old persons' homes and what have you. They shouldn't be there. I mean, my daughter, when she was picked up at the accident scene she had a Glasgow score of 2, so the medical people - not knocking them - they say, "Righto, well, you know, your daughter is suitable to be warehoused" - that's the crude expression. You wouldn't recognise her today because she's been part of a family, she's been interacting with the community and what have you. Brain-wise, intellectually-wise, she's 100 per cent there, but the number of times she's said, "Dad, I feel trapped in my body," I mean, I've just lost count. There's lots of people like her around.

Moving on. Tax concessions and credit, I've suggested here. Alternate means of subsidising carer payments for families. There are those who choose to volunteer and care for the disabled or seriously ill of their own volition and out of love, commitment and time availability. Others are legislated volunteers or detained and conscripted volunteers like us. There would be many of us in Victoria. Collectively we're the invisible asset of and to the Australian community. We are also a productive and measurable asset to both state and federal governments; they are not accountable but we have to be accounted to. Volunteers and the volunteer are worth billions in unpaid dollars to the national Australian economy. With a fast ageing population and the growing disabled client base, where will the required carers come from? Increasingly this responsibility, in my opinion, will pass to family.

I don't know what other people's experiences are but that's what I can see is going to be the safest and most secure way for my daughter. I hope by my example that my kids are going to follow through and look after her. So, suggestions: take for example a family with one wage earner, three children. A second child 10 years old could permanently disabled through an illness like MS. This high dependency requires full-time care. The sole breadwinner earns $55,000 a year gross. The mother is the principal carer. It's tiring work; would be fortunate to get a break on the weekends when her husband is at home and would not be able to afford paid respite care. The direct assistance to a family like this should be, or in a similar situation, no income tax to be paid on the first 50,000 of income earned, thereafter as per the normal tax schedule. In addition, the family would still qualify for normal social security family-type benefits.

The number of families in Australia in this situation, given the suggested tax concession, would have a minimal to negligible effect on the national income tax revenues, yet it would be given immediate impact on the family needing the benefits or disposable income. This form of assistance would be protected from cost-cutting reviews of bureaucrats who seem to indulge on a regular basis, when they come to reviews, the tax system. I've made other suggestions here in relation to tax credits and also rehabilitation. The benefit that my daughter got from going to the Sporting Wheelies gym - I used to take her every day in the early stages - was just immeasurable really. I mean, she was interacting with other people, she could see them working, but also she was enthusiastic about her thing.

So I have a daughter today who now can walk 140 metres per day. I take her down to the Shorncliffe pier with a walking frame. They had said she'd never do anything like that. That gym made all the difference. Now, if you're going to have the social insurance where you're going to need to get these people mobile and what have you, there needs to be some sort of incentive to the gym people in general. Say, "Okay. Well, if you take 10 people of disability and put them through, we're going to give you a 2 per cent discount or allowance off your tax return" - whatever the incentive is, but the person who is going must still pay upfront, you know, two, $2.50 because they are making a contribution to whatever. So the principle that they have at the Sporting Wheelies is great. You go in, you pay a low fee. You're still making an outlay but the benefit - the government is benefiting because the person is getting better and they're getting more mobile and more independent.

Suggestions for legislative change. Oh, dear - well, you've got it in front of you. I made quite a few suggestions there.

MS SCOTT: Yes, we've got the copies.

MR DENNISON: There's quite a few here. I don't want to sort of bore the clientele and waste too much of your time, but they are there.

MS SCOTT: Cyril, we're just coming towards the end of your time anyway and we have got your submission.

MR DENNISON: Yes.

MS SCOTT: So thank you very much for that. I just wonder whether you want to wrap up with just a final comment.

MR DENNISON: Yes.

MS SCOTT: I guess if the TAC legislation did not have that 40-hour limit - 40-hour per week limit - would that have addressed most but not all your concerns? If we kept that in mind in thinking about design, would that be the thing that you would - - -

MR DENNISON: It would have made a huge difference to our particular situation - huge. I mean, by putting that, that interfered with common law. Now, common law - I know I shouldn't be talking about the amounts of money here, but my daughter was particularly badly injured and a brain stem haemorrhage. So it affected her ability to walk, paralysis down the right-hand side, which has slowly improved, but her speech, her vision, many things. If she'd got the settlement she was entitled to, we would have been able to have, say, hired care and what have you, which would have made it a lot easier on the family, except that we've had to change the whole thing. Now, I'm not blaming my daughter for our situation but the legislation there is wrong. If it's happened to me, I'm sure it's happened to dozens of others already. What we don't need is Commonwealth legislation that's going to come up with the same thing with a time limit like that. I think it's repugnant, myself.

MS SCOTT: That's been very clear. So thank you very much for that. John, are you comfortable if we wrap up now?

MR WALSH: Yes. Thank you, Cyril.

MR KALISCH: Thank you very much.

MS SCOTT: Thank you. Well, we're now going to break for lunch and if we could be back here at 1.45 exactly, please. Thank you.

(Luncheon adjournment)

MS SCOTT: Good afternoon. Genevieve, thank you for appearing before us today. For the record, could you just state your name and the organisation you represent?

MS ATKINSON (Y): My name is Genevieve Atkinson and I'm from Youngcare.

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

MS ATKINSON (Y): Yes. Thank you. Look, we'd like to say first of all thank you very much for the opportunity to present today. We're really excited to be participating in the inquiry and also that the Productivity Commission is actually looking into this critical issue that's affecting millions of Australians. We have provided you a full copy of our submission and I suppose I had hoped today that I could just take the opportunity to run through a few of the responses to the first issues paper.

As you may be aware, there are currently more than 6500 young Australians with high care who are living in aged care homes simply because there are no other alternatives or very few. In addition to that, there are more than 600,000 young Australians with severe or profound core activity limitations, many of whom who are being cared for at home by family and friends due to advances in medical technology and the high standards of Australia's health system.

The number of people with high-care support needs is increasing and people are surviving car accidents and those who are suffering degenerative diseases are now able to receive medical assistance to support and prolong life. However, while these advances are being made, we still strongly believe that young Australians with high-care needs are still falling through the cracks, that young Australians deserve a life that has hope and possibility but, most importantly, dignity, and we believe that this is simply not happening today.

I just quickly wanted to touch on what Youngcare has been doing over the last five years. We're committed to raising awareness of the issue of young people living in aged care and the broader issues, so that we can drive policy change and, most importantly, create real choices for young Australians and their families. We do this through a number of ways. In 2010 we will continue to focus on raising awareness, through marketing and fundraising but also in lobbying government for policy change.

We have three key programs. Our Youngcare Connect helpline, which is a one-stop service; an at-home care grants program, to help people stay at home for longer; and through developing a range of accommodation. Youngcare strongly supports a national disability insurance scheme. We believe that an NDIS has the potential to provide choice and care and accommodation options for young

Australians with full-time care needs.

We believe that it is only through the introduction of such a scheme and the possibility of funding for lifetime care that young Australians with complex support needs have access to a range of things, and this includes choice about where they live and how they are supported; funding and support options that are client-focused rather than provider-focused; ready access, most importantly, to information about programs and services and funding that will help them in a range of aspects of their lives; access to comprehensive and individualised service planning; and care that is provided by a skilled and competent workforce.

There are four areas that we felt strongly about within the issues paper. The first was eligibility; the nature of services was our second; the magnitude of funding that we believe is necessary; and also how stakeholders would be involved and represented in the scheme. Just on the point of eligibility, as I touched on earlier, Australians with high-care needs are currently disadvantaged and in crisis, with aged care often the only option. We believe while there is nothing wrong with aged care per se that for young people this is simply not appropriate.

So it is our recommendation that an NDIS must address the needs of people with high-care needs in the community who don't fit neatly into health or disability care models and are currently falling through the cracks. We also believe that it should be a recommendation that there be a more coordinated and comprehensive approach by the federal government to address the medical, social, financial and emotional needs of people in need of high care. Currently you have aged care, health, housing and all disability talking in different ways, and we believe that this has to be rectified.

As far as the nature of services and are there any services not provided that we believe should be looked at as part of the scheme, when you look at the figures of people with profound or severe disabilities they are simply only going to increase. We believe that the scheme must contribute to meeting the requirements of people with high care, in terms of care but also in housing. Housing for the client group that we represent is a major issue when you look at the limited choices with which people in this group are faced. 60 per cent of people who call our Youngcare Connect helpline are calling about the issue of accommodation.

So we believe that further investigation needs to be undertaken to meet the growing demand in disability housing, particularly for this high-care group and also that work needs to be done - and Youngcare is currently starting to look into this work - on how to establish private sector involvement, with the government, in working together to build more disability housing that is affordable but also is replicable.

What is the magnitude of funding? Youngcare has been a critical supporter and player in the Young People in Residential Aged Care program, which is a program of the federal government. The program is $244 million over five years. Our 16 residents who live in the Sinnamon Park Apartments in Brisbane are funding under the YPRAC program and that's at $120,000 per year, which is given to Wesley Mission Brisbane. When we finish our building on the Gold Coast, which will be home to seven apartments, the Queensland state government has committed funding of $3 million over three years to that building.

When we look at the YPRAC program figures that have recently come out, 90 people were moved out of nursing homes over three years, 300 people were provided with improved services within aged care, and 150 were diverted from inappropriate admissions to aged care, which is wonderful news. However, if you look at the figures of 6500 young people and the 600,000, it simply just doesn't add up. We believe that an NDIS can meet the funding needs, which are incredibly high, and we understand that if you're looking at 120,000 per person over perhaps what is 20 years that's a lot of funding.

But we strongly feel that an NDIS must be provided to individuals to provide appropriate levels of care to meet their medical, respite, rehabilitation and social needs. Finally, on the issue of how you could involve stakeholders, since 2005, Youngcare has focused on giving a voice to people who simply had not been heard. Awareness is a major part of the work that we do, in making sure that people understand that there are people in this situation, and we believe it is something that the Productivity Commission must investigate.

Over the last 12 months the disability sector has spent a lot of time discussing the pros and cons of the proposed scheme, what it could look like, how far it could go. But we believe that a key stakeholder that you must now turn to is the Australian public. Before the Australian public can recognise the urgent need for a better system that can provide lifetime care they must also recognise the rights of people with a disability, they must see that there are people who have disabilities that can contribute and participate in Australian society and must have that right to do so.

So it is our belief that a national marketing campaign must be undertaken by the federal government with the backing of the sector to ensure awareness of the issue and then that campaign would pave the way for Australians to be open to the concept of funding a scheme such as the NDIS. So that's all we really wanted to bring to your attention today. As I said, we have presented a fuller submission to you. We hope that our contribution assists in some ways to your thinking and we wish you the best of luck with your endeavours.

MS SCOTT: Thank you very much. I am interested in exploring with you the type of housing and accommodation services that you offer, how you arrived at the right configuration, type of choices, whether you're handling the issue of people coming together who may not know each other, or how do they make an informed choice. Could you talk about that, and the time frames, and how you have settled those arrangements.

MS ATKINSON (Y): Sure, and there's a lot in those questions. I think if I can start by saying that Youngcare firmly believes in choice in accommodation. I prefer to live in the inner city, my colleague next to me prefers to live in the rural experience and we believe that people with high-care needs should be no different. So we believe in choice. The first building that we have completed is an apartment-style building, but when we look to move to Sydney we're currently looking at more of a group-home option.

We have been in discussions with building companies where we could look at doing a building with a private company where it's just a normal house that is disability-accessible. The Gold Coast building, it is seven apartments. I suppose the underlying premise to Youngcare's philosophy of accommodation has always been about the best possible kind of building that we could build.

MS SCOTT: Just on that, Genevieve, if I can direct you a little bit.

MS ATKINSON (Y): Yes, thanks.

MS SCOTT: I visited some facilities that were almost a traditional group home and then cottages. We have heard - I don't know if you were here earlier - but - - -

MS ATKINSON (Y): No.

MS SCOTT: - - - people talking about maybe an arrangement where people who were interested in some support in accommodation but not full-time supervision could purchase or rent an apartment and then maybe the eighth person provide support care. You're probably talking about the high-level needs.

MS ATKINSON (Y): Yes.

MS SCOTT: Could you talk about whether the seven apartments almost looks like an aged care facility but it's doing it with a younger population. Could you talk about how it's different?

MS ATKINSON (Y): How it's different from an aged care home - and I have worked in the aged care sector - is that they're almost like one-bedroom apartments in a bigger apartment complex. So you have your own kitchen, you have your own bathroom, you have your own lounge room. The difference that we have is that the group that we talk about do have 24 hour, seven days a week care needs, so we have registered nurses that are there. So there are some similarities in that sense to an aged care facility. But that's not to say that for the Gold Coast apartment we wouldn't have staff there as greatly as we do in Sinnamon Park.

MS SCOTT: Thank you. That's very useful. Did you encounter any particular problems in terms of planning requirements or neighbourhood reactions - - -

MS ATKINSON (Y): All of that. For example, at the moment on the Gold Coast we're having a major infrastructure issue with council, we're asking counsel to waive some fees for us. We have had neighbourhood issues, you know, "Not in my backyard." So there has been all of those issues. Just on the issue of people in the building and when we have an opportunity for a new resident to move in, the residents have the opportunity to participate in who is coming through. It has been an issue, it has been something that we have learned from, the right of people to choose who is going to be living in their apartment building.

I think the care provider would also say it has been a vexed issue for them. We have two groups of people who live at Sinnamon Park: one is the group who have multiple sclerosis; and the other have acquired brain injured, and the care provider would certainly say that they have had different issues with that mix of people together. While Youngcare raises the funds for the building and is involved in the actual building, we have no involvement in the processing of who decides to live there. Those kinds of questions are probably better answered by Wesley Mission Brisbane.

MS SCOTT: Thank you very much.

MS ATKINSON (Y): Thank you.

MR WALSH: Genevieve, thanks for that. I'm very interested in this model. Do you have any information on the staff to resident ratio?

MS ATKINSON (Y): There's 16 residents. During the day we have eight staff, from I think it's 3 o'clock to 9 o'clock it is six, and then overnight it's two. But I can provide you from Wesley more detailed information about that.

MR WALSH: What is the view of the disability sector to this?

MS ATKINSON (Y): To that model?

MR WALSH: Yes.

MS ATKINSON (Y): Look, I think we have certainly found over the last two years that there are many people who are anti the model, and I certainly wouldn't shy away from that. We have had many discussions with people who say that we are institutionalising, that it's an institution. If you're in a four-bedroom house there are issues. Institutionalised care is not necessarily about the building, in my view, it is about the style of care.

It is something that we are very conscious of every single day, for example making sure that people get to choose what kind of food they want, that there are individualised options. I think that if you haven't been there it is very easy to say it's another institution. I think when people go there they realise that it is very much one-bedroom apartments in a different setting, but certainly it's always first and foremost in my mind to make sure that it is more of an individualised experience rather than an institutionalised experience.

MS SCOTT: Because you've got people who have high-care needs I imagine that they may have quite restricted opportunities to be outside.

MS ATKINSON (Y): Yes.

MS SCOTT: So in fact I suppose the community has to come to them.

MS ATKINSON (Y): Absolutely. That's a very strong philosophy that Youngcare and Wesley Mission work together on, and I think that's sometimes the difference. People say, "This group of people, the Sinnamon Park residents, are not living in the community." Unfortunately, because of their care needs, they can't necessarily get out as much as they would perhaps like to. Where possible, we have one lady who is very involved in her church group, so there is a strong volunteer base of people to make sure that she can get out to her church group at least twice a week.

We have a young gentleman who has an acquired brain injury who attends TAFE, so it is very much on a person-by-person experience of making sure as much as possible they can get back into the community for their needs but we also do bring in a lot of experiences and community groups to make sure that they get to participate.

MS SCOTT: I've got one last question and I know David is keen to ask a question. It's Youngcare now but in 40 or 50 years you're going to have something called Youngcare - - -

MS ATKINSON (Y): We would hope to be gone. We would hope that we're not having - that we could close our doors and that NDIS has sorted out - that there are no people living in aged care unless they really wanted to. I have visited many aged care homes in rural and regional Australia where for families that's the only place that is close to their home where their son or daughter can live and I think that's completely appropriate as long as with the YPRAC program you're getting some top-up rehabilitation experiences and services. In 20 years' time Youngcare - if we could close our doors that would be brilliant which is quite unusual but - - -

MR KALISCH: I've got one question along those lines and I suppose my expectation would be that people, once they're safe, secure, comfortable in a form of accommodation will want to stay there.

MS ATKINSON (Y): Yes.

MR KALISCH: Just following up that question a little bit, if you did have someone who came into your facility at the age of 30 or 35 and we know that people with disabilities are now living longer, that they're living longer than was perhaps expected 20 or 30 years ago, I can envisage that someone might be, say, still living at 60, 65 and 70 and Youngcare, as I understand it, is not necessarily pitched at that age level. Would you expect that person to leave the facility for a residential aged care home or would there be that accommodation?

MS ATKINSON (Y): We've only had one building and Griffith University is currently about its first - they've just done a two-year research into the facility and how it has worked and I keep coming back to the apartments is not the only style of building we would like to build, we're looking at different models. But we haven't yet faced that question, the residents have only lived there for two years. We have one young gentleman who I talked about who goes to TAFE and he will probably get to a point in the next year or two where he could change, as many of us do, where he's living because his needs are not so high any more. So we are going to have to have those experiences to work out where to next because if someone has been there for 30 years and they're turning 70, it's probably time for them to move to a different style of accommodation.

It also goes back to the funding. The residents who live there are funded under the YPRAC program and the YPRAC program is focused on people who are 50 and under, even though it says 65, but they're not. We have the additional problem that our residents are no longer funded so Wesley Mission Brisbane is no longer funded for them. So there's a whole range of questions that we are yet to answer.

MR KALISCH: The other question I have is around - I suppose if we're looking at any scheme that would fund accommodation and services, just the nature of the funding for the buildings and then also Wesley Mission and the relationship that you have with them. Is private financing or is there just public - - -

MS ATKINSON (Y): With the Youngcare style of building that we've done at the moment, for example, the Gold Coast building we've received $2.52 million in economic stimulus funding for that building but everything else that we have raised is from fundraising. But we can't fundraise for 16 people or seven people at a time and there's if 6500 people we recognise that we need a better model of providing housing and that's why I personally feel very strongly about establishing how the private sector can be involved in disability housing in the same way that when you look at social housing and when you look at things as the NRAS scheme how can we get more people to recognise this style of accommodation that we need.

As I said earlier the biggest problem that we have is that there is not enough physical stock in Australia for people to move to appropriate accommodation to meet their needs and that's the biggest issue that we have.

MS SCOTT: John, would you like to chip in with any questions?

MR WALSH: The questions I have, I don't think have any answers, Patricia.

MS SCOTT: Okay, that's fair enough. I've got maybe one last one for you then, Genevieve, the 16 people who are now at Sinnamon Park, did they come out of nursing homes?

MS ATKINSON (Y): Some have come out of nursing homes and some have come from home, so there was a mixed group of people. Some came from hospitals and some came from other styles of accommodation.

MS SCOTT: Thank you very much for your time.

MS ATKINSON (Y): Thank you again for the opportunity. We really appreciate it.

MS SCOTT: Right, Maureen Fordyce, Nedzad Nuhovic and Maria. Good afternoon and thank you very much for intending today. Would you like to introduce yourselves, your organisation and make an opening statement, please.

MS FORDYCE (AAI): In terms of an opening statement, how long do you - - -

MS SCOTT: If you outlined things for, say, 10 minutes or so.

MS FORDYCE (AAI): Okay. yes.

MS SCOTT: In total you've got 25 minutes and we'd like to take some time with questions.

MS FORDYCE (AAI): Okay, thank you. My name is Maureen Fordyce, I'm the coordinator of AMPARO Advocacy. AMPARO Advocacy is a non-profit community organisation that provides individual and system advocacy on behalf of vulnerable people with a disability from a non-English speaking background. The organisation receives funding the Department of Communities disability services. So we advocate for people who are vulnerable because their language or cultural differences makes it more difficult for them to negotiate and access services and systems. We also, in terms of our systems advocacy, aim to influence positive sustainable change to policies, practices and attitudes within community and government. Our vision is that people with a disability are to be accepted as part of the Australian community with access to information and services and benefits et cetera so that they can be fully included and contribute to the family and community and broader community life.

In terms of today I'm going to speak just very briefly about some of the things that we think are essential and any new scheme of support for people with a disability but mainly I felt it important for the commission to hear from Nedzad who is a parent of a young man with an acquired brain injury who I have been involved with in a number of ways over the years. So today I'll speak briefly and then I'll hand it over for Nedzad to talk about his experience and his son's experience in accessing supports and some of the good things that have happened and some of the more difficult things that have happened and I think there are some lessons there for the commission in terms of any new scheme.

AMPARO Advocacy believes that any new scheme obviously would need to adhere to the principles outlined and stated clearly in the Convention of the Rights of Persons with Disabilities in order to protect people with disabilities' rights as citizens, so that's first off. We would like to see the scheme obviously to be - and access to the scheme should be an entitlement for all people with disability who need support and not limited to people with profound and severe disability. There are many reasons for that and we'll outline those in a submission to the commission. We believe people should be entitled to receive timely and appropriate support and that the scheme needs to recognise that people's needs do change over time and so people's support needs to be reviewed regularly so that what happened with Jenan and his family doesn't occur in the future for other families. That's very important.

Also early intervention is extremely important to assist people with a disability and their families to access support when they need it and not have to go through what many families, including Nedzad's family, had to go through. We believe that people with a disability should be entitled as an option to manage, design and direct their supports. The new system should provide funding directly or the option to people to be funded directly to the person with the disability and they should have the option to plan and design and direct their support. This reduces unnecessary administration coordination costs and then if they choose they can have the right to obviously hand over some of that or all of that management to a service provider. Also portability is absolutely crucial to ensure that if people are unhappy with the service that they can take their funding at their discretion, without any justification, to another service provider or to choose to manage the funding if they decide to. So there are some things that AMPARO Advocacy is very concerned about that should be implemented in any new system.

In order that a system be designed and developed so that supports are provided in a culturally responsive and sensitive manner, we think directly paying families which is some of what Nedzad will talk about is one way to ensure that services are culturally responsive. I would lastly just like to say before I ask Nedzad to speak is that in order for people to have equitable access to support under any new scheme, people from a non-English speaking background currently don't have equitable access to services and supports and that's largely due to many systemic barriers that exist, many of which have existed for some time such as myths and stereotypes about disability; lack of information about rights and entitlements for people; lack of information about services; lack of access to interpreters; lack of funding for interpreters; lack of service provision, so any new scheme would need to address some of those barriers. Some of those barriers are generic, some of those barriers need to be addressed through this scheme. We'll put more information about that in our submission.

I would like to hand over to Nedzad now for Nedzad to tell you a little bit about his son and his story for his family.

MS SCOTT: Thank you.

INTERPRETER: My name Nedzad Nuhovic. I was born on 12 January 48 and I came to Australian in September 1998. After two years in this country, that is 2000, my youngest son suffered a traffic accident in which he obtained brain injury and he became 100 per cent disabled. His name is Jenan Nuhovic and he was born on

20 September 1977. Until the accident everything went fine and life became nice again here. But since the day of the accident my life and my family's life has completely turned around. For my wife, Mirsada, and myself from that day on there was only concern and the constant care for our son and the hope and faith that hopefully one day he'll get better. During those two years and four months while Jenan was in hospital there was not one day when we did not visit and give our support to him.

That period was very traumatic for us because of Jenan's physical and psychological condition. For a few months he was in a coma. Another source of concern for us was that there was no information about the system of assistance that could be offered to us. The first big problem started when Jenan's physical condition improved to the degree when he wasn't getting medical treatment and the manager of the hospital was putting pressure on us to take Jenan home from the hospital. At that time the biggest problem were his seizures that he had occasionally and because of the seizures somebody had to always be with him. We had no information about whom we could contact for assistance and once he's out of hospital where should we turn to. We were given a list of nursing homes and we were advised that we should look for a place for Jenan in one of those nursing homes in Brisbane; it was a list of nursing homes in Brisbane and surrounds.

Then we rented a house which was not nearly adequate for Jenan's needs and hospital probably wouldn't have agreed that it would be suitable for his accommodation. My wife and I visited about 40 nursing homes in Brisbane and surrounds and that was a very difficult time and we had very emotional moments and I'm sorry I'm getting emotional when talking about it. In most of these homes we were asked a question, "How come we were thinking of putting such a young man into a nursing home where mainly old people were staying?" We contacted also the Department of Housing and tried to apply for some kind of adequate housing for his needs so that on discharge from hospital he could have adequate housing. Our three applications were knocked back with a justification that Jenan's case was not difficult enough, that there were many more difficult cases and that our case didn't have priority.

I requested an interpreter for my interview at the housing department. During the interview I asked the officer in charge how he would have felt if he was in my place, just to put himself in my shoes. I've got from him a reply that I'm actually very grateful for. He advised me to contact an advocacy service. He said that the advocacy service could give us support with our application for housing. I got in contact with the advocacy service so they speak up for you. From that moment on everything went easier and quicker in terms of our accommodation for our son and for us as well. One month later Jenan was in the first place on the priority list for priority housing. For me it was incredible that after three of my applications were knocked previously that after this so very quickly we could get on the priority list and get some place.

From that moment on the occupational therapist from the housing department started visiting the hospital to find out what Jenan's needs were. After that we were given the answer that at the moment they didn't have any adequate place of housing and also they said they would look for an appropriate location where they would build an appropriate house. That process went slower than expected. It took four years because of some complications that I wouldn't like to get into. But eventually we moved into a fantastic new house which was absolutely adjusted to Jenan's needs. In the meantime we found a house to rent which more or less was suitable for Jenan's needs and the hospital gave their permission that he could move in there. So finally two years and four months later, that is February 2003, we finally moved into this new house. We took Jenan out of the hospital and moved into this house.

At the same time the advocacy service contacted several different services looking for support for us because caring for Jenan was a 24-hour job. We also had no knowledge, no information about whom contact. We had no idea where to turn for help. Soon several services started sending their workers to us who were giving us a few hours each of help with Jenan. It automatically brought some relief for us but at the same time there was some trauma associated with it. It is to be accepted that we had no choice in choosing who would come and work with Jenan and who would come into our house. It happened that some services changed a worker coming to us almost every week. It was very traumatic because sometimes the person who came to work was not a person who was suitable for that job.

In December 2003 with the help of the advocacy service we received family support program assistance from the disability service and then it became much easier because we were granted more hours of assistance with Jenan. Talking to the disability services we found out that we could choose the person who would work with Jenan and that that person could be employed through another service and that person then could be paid from this family support program. That service also charged their own administrative fees. We were very happy then because then we could choose a person from our language background or from our culture, from our mentality, the person whom we got to know very well and someone who good friends recommended to us.

That moment for us, that was very positive for our family. It was a big psychological relief. But I must say that there was still some nervousness primarily because our own psychological condition because of the hours of not sleeping, irregular sleeping patterns. It also meant a loss of privacy of our own private life because that person was always present with us. In the beginning of 2006 we received from disability service information that some families employ themselves a worker and that way they save that money that would be paid for administrative costs for other services, so that money could instead be used for giving more assistance to

Jenan. We were happy to accept the task of doing all the administration all ourselves and that way instead of 22 hours of help, then we got 30 hours of help with the same amount of money.

Finally in November 2005 we were given the keys to the new house. We were very happy because the house was wonderful. One could only wish for something as good. We work a lot and exercise with him. His physical condition is now quite okay like me. His health is mainly good without any major problems, thank God. There is progress but he still cannot speak. He's trying to but he still cannot speak. He cannot care for himself. For example, he cannot sit without support. He can eat, but like a baby. That means he still requires 24-hour care.

Now, after almost 10 years for us there is this question about the future. My wife and I are getting older and older, not younger and younger. Our strength is getting weaker and weaker and we cannot work as hard now as we could two years ago or four years ago, five years ago. The assistance that we are getting now is actually one-third of the total need for care in hours. For us it is a big psychological burden because of this question, what shall we do? That's why we started talks with disability services who are also helping us in regards to Jenan's future. We started working on some concrete plans. They're saying that a plan will be made and that it will be all right. But there is the question mark about the financial situation. Without financial support it would not be possible to look after him properly, especially if we will one day not be able to do the job and even so it's only one-third of the time that we are getting assistance. So when we can't do it, what will happen if there is no financial support.

MR NUHOVIC: That's it. Thank you very much.

MS SCOTT: Thank you.

MS SCOTT: John, a question or two?

MR WALSH: Thank you very much. I'm struck by the difficulty that you had to go through over those years. I think you said it was two years and four months that your son was in hospital.

MR NUHOVIC: Yes.

MR WALSH: I'd be interested to know when you think he could have left hospital if you'd had accommodation ready.

INTERPRETER: It was after eight or nine months in the hospital that Jenan's health improved so much, that as far as his physical condition was concerned, he could have left the hospital but there was no-one to take him. It was just a question where to?

MR WALSH: This may be a difficult question for you to answer but I'm trying to deal with the non-English speaking background advocacy. To what extent do you think the difficulty in finding accommodation was due to it being available or you not having sufficient advocacy to sort your way through the system?

INTERPRETER: I didn't know where to turn. The hospital only gave us the list of the nursing homes and I didn't know where to find a solution, where to find assistance, where to turn at all.

MS FORDYCE (AAI): Can I make a comment here. I was involved at the time with the family and I think being from a non-English speaking background did make it more difficult in terms of the family and Nedzad tried for a number of applications with housing but it's very difficult when English isn't your first language and you're filling in those application forms. It's difficult for everybody to know what information is required. It's even more difficult if English is your second language to know how to put that information together and it only took a month when someone assisted them, which I think shows that language and cultural differences did have an impact at that time, as well as a lack of information being provided generally by the hospitals.

INTERPRETER: I would like to add, just on the basis of my experience and my family's experience, if there would be some kind of service from either the hospital or the family could contact straightaway, so that some assistance could be organised straightaway, either through the hospital or the family directly contact.

MR KALISCH: More interested - a quick question for you in terms of your understanding of other advocacy groups and people also engaged in the sector, I mean is this a common experience of not being able to access accommodation when it's required?

MS FORDYCE (AAI): For many people with disabilities, I mean the housing sector in Queensland is in a state of crisis. Under the Howard government we had 10 years of neglect of not building, of reducing funding to the Department of Housing and so it is far more difficult now to get access to appropriate housing for people with disabilities who require an accessible home than it was even when Nedzad was trying to get a house for his son. So it's extremely difficult to get appropriate housing. I would just like to say I think housing is a separate issue to support. Housing I would see as the Department of Housing's obligation and support is a separate - should be treated as a separate issue.

MR KALISCH: Perhaps a question about advocacy services. Do you ever perhaps see the day when advocacy services won't be required?

MS FORDYCE : I think that would be fantastic, yes, obviously. Unfortunately - I regard myself as an optimist but I don't know that that day will ever come and there's no enough advocacy in Queensland or probably Australia, but Queensland certainly there's not enough advocacy. Without advocacy many of the things wouldn't have happened for this family and there's many families out there that can't get advocacy who don't get advocacy who don't know about advocacy because it's so limited, you can't access, and who then miss out on getting onto priority housing because they haven't got an advocate.

MS SCOTT: Thank you very much, Maria. Thank you Nedzad, thank you Maureen.

MR NUHOVIC (AAI): Thank you very much.

MS FORDYCE (AAI): Thank you.

MS SCOTT: I now call to the table Rosemund Harrington, please.

MS HARRINGTON: My name is Rosemund Harrington. I'm a PhD student and I'm actually looking at the impact of motor vehicle accident insurance scheme design on quality of life after severe traumatic brain injury, comparing people in a no-fault model, Victoria, with people in Queensland, which is a common law system. so I looked a lot at insurance and how they operate to meet people's needs. I'm comparing people in a no-fault scheme against people in a common law scheme where they have to go through a legal process to access funding and establish someone else's fault in that process, and those people who obviously don't have access to insurance within Queensland who've had a road traffic accident.

I've come to this on the background of actually working at Jacana Acquired Brain Injury Services, which is a residential and rehab facility, slow-stream rehab facility for people with brain injuries. On the back of that I've been an occupational therapist working within Queensland for 20 years and I've worked across residential mental health facilities, residential aged care and in community-based settings as well. My last position at Jacana, apart from education, was to really look at trying to create pathways for people to re-enter the community when their rehabilitation needs had been met and they were at a point of transition where they would have a much better quality of life being out in the community. I guess the other thing I'd just mention is that I was for quite a number of years a carer of a person with a brain injury.

I think I've given you a summary, a written summary, and will provide a more detailed submission. I think one of the key focuses that I'd like to talk about is the impact of increasing marketisation of lifetime care and support services, so really putting a dollar value on care. I think that there are some ethical considerations around that and also some implications on how that will affect the way service systems develop within different states.

But first I'd just like to talk a bit about a few common points. One of the questions that you've asked is who should be eligible for a scheme, and I think that if you want to look at the populations in Australia that have been most let down by the disability care and support system you'd have to go to aged care and look at what the demographics of people who have ended up in aged care, which is not an appropriate response for young people with disabilities. In 2010 the Australian Institute of Health and Welfare said that almost 47 per cent of people in the - young people in residential aged care program registered for that had an acquired brain injury and 29 per cent had a neurological disability. I think that that really highlights that the system lets down these people who acquire disabilities at a later age. The system hasn't had the capacity over a long period of time to respond appropriately - develop systems to respond appropriately to their needs.

I think individualised funding streams are a fantastic idea but I don't think that throwing money at a problem is the only answer. I think that really alongside any individualised funding stream you need to make sure that there's a variety of services available which people can purchase. If what becomes available is just left to people having money without having the knowledge of what the services are but also some investment by government in developing the appropriate services for people in partnership with private industry and non-government organisations, that increase in funding to these people won't solve the problems.

So I see the three primary things that I really think the scheme needs to address is flexibility to respond to individual's needs, especially at periods of transition, which the gentleman here's story obviously indicates - so an ongoing review process where people work in partnership with somebody who is an advocate and can help to guide them through the services. Another key factor that I think is important and also a mechanism for coordination of services. I think the case - the gentleman speaking before me really highlighted how lining up care and housing is really important to meet people's needs.

Couple of other general points that I'd like to make. One is that if funds are all pooled into one budget for a person there is a risk that important things like respite for carers and access to aids and equipment might be put to one side. I think that that is something that I've certainly seen in the aged care sector and is a potential factor if a service organisation holds an individual's budget. Access to aids and equipment is essential for people to increase their independence; it's essential to protect the people who care for them, if they have high physical needs, from injury; and also improving communication. I think access to assistive technology for communication is vital if people are going to be able to communicate their needs.

MS SCOTT: I don't want to - normally I wouldn't interrupt someone's opening statement. Can I just - I think I need you to go a little bit further. Why would individualised packages per se lead to less government action or less funding going to aids and equipment? Could you just explain why - - -

MS HARRINGTON: What I'm saying is, if you have pool funding. So, for example, if a service provider is given a certain amount of money to provide a service, to provide someone's care and support needs, that money is generally needed to cover their equipment needs because they may give up their eligibility to a state-based equipment program as part of a package. That certainly happens in the EACH package. Respite for carers is not necessarily incorporated in that package. People may not be able to bank hours from care so that a carer can actually go away for a weekend. In Germany they have a separate carer's respite allowance where they have four weeks of funded respite for a carer. It's separate from the individual budget and that way it ensures that money does go to that area; that it's not overrun by care needs.

MS SCOTT: Thank you.

MS HARRINGTON: Certainly with equipment as well, in aged care that's been a huge issue, I think, that equipment is attached to the individual funding and people don't get the equipment they need. I mean, it's quite obvious from the YPRAC program, a lot of money went into funding people who might not have had an appropriate wheelchair for five years.

I think that when talking about developing service system capacity, actually having the services available for people to purchase, a really good example of how that was done within Queensland is the Spinal Cord Injuries Response and that was a cross-government response to people with spinal cord injuries exiting hospital. It lined up funding within each of those departments, a quarantined bucket of money for people with spinal cord injury so that at point of discharge their housing, their equipment and their care were all available at the same time. There needs to be a role of government in ensuring a coordination of services so that those services are available when they're needed. I think there's an ideal opportunity at the moment to do that with healthcare reform where there are local hospital networks being established which other government departments could partner with so that local level responses are made to ensure services are available for people.

I'll just make five quick points about increasing private investment. I think the Youngcare model is great in that private investors have given money to this organisation but they haven't maintained control over what happens to that money. They've given it to build facilities and then the care delivery is separate. That's different to setting up a private organisation that provides care. I think within Queensland one of the things that has influenced our Disability Services Act is if one service controls every aspect of somebody's life, then a person becomes vulnerable to neglect. So I see that it's very important that there's flexibility in the system for people to move between providers and that any sort of accommodation model is monitored and that people can receive services from people outside of that service.

I think a key problem with the way that accommodation services are set up at the moment, and providers will tell you this, is they're given a certain amount of money to provide accommodation for people, but what happens when the person becomes more well and can move into a more independent environment? They can't take that money with them. So they get stuck. I think that that's - there's obvious cost savings if you can move people to more independent environments. I think I'll stop talking because I've talked about the other points in the submission I've given to you.

MS SCOTT: Thank you very much. I think you're unique amongst all the people submitting to us. I think if I've got it right, you have been a carer in an unpaid capacity, you're an occupational therapist, you're a PhD candidate actually studying subjects very close to our areas of interest, so I think you bring a unique perspective. You're looking at the TAC scheme in Victoria. I don't know if you were here for the earlier evidence from a gentleman, Cyril Dennison. Were you here for that?

MS HARRINGTON: No.

MS SCOTT: Well, maybe it's the case that you'd like to look at the transcript when it becomes available. Some people have very glowing things to say about the TAC, other people have critical things to say.

MS HARRINGTON: Definitely, yes.

MS SCOTT: There are other insurance models, for example, the Accident Commission scheme in New Zealand, there's a Lifetime Care scheme - very small - in New South Wales. Having looked at those two schemes, would you like to make some comments about the TAC scheme in terms of what you think is good and bad about that scheme?

MS HARRINGTON: I'm halfway through my PhD so I've still got some field work to do in Victoria. I guess my specific interest is brain injury service system development and certainly the story before, the man who spoke before, the service system hasn't developed in Queensland and I think most people would acknowledge that. In Victoria there's been a very strong private sector service system developed for people with brain injuries which has been really fuelled by the TAC because 60 per cent of people with severe traumatic brain injury get their brain injury from road traffic accident. That has ensured that people have the services that they need and the TAC has changed over time in how it meets those needs.

I think there are some issues related to have a private service system, one is inequity between people who don't have their brain injury from road traffic accident obviously and those people who do. Large service providers usually centralise within cities so if there's not some coordinated planning that ensures that there are services outside of city areas, then that can be a problem as well. I've also looked at the New South Wales scheme and it has quite a different approach. It's structured it's lifetime care and support scheme on top of an already well-developed service system, which was progressively developed with the assistance of their motor accident insurance authority, and that service system has ensured that there is a network of service providers in the public sector across the whole of the state.

For Queensland, because of our geographical distribution of our population, that's going to be a really key issue. If funding is funnelled into privatisation, private providers don't necessarily set up in rural areas and that's quite common for people who technically are insured under our scheme not being able to access the supports they need because they just don't exist, or, otherwise, service providers setting up in that area and charging very costly services which means that money doesn't go as far.

MS SCOTT: I know David will want to ask questions as well, but if you had A, B, C, D and D is a failure, would you feel comfortable to give a pass mark or give a mark A, B, C, D - D failure - say, comparing the New South Wales scheme, the Queensland scheme and TAC?

MS HARRINGTON: You're asking me to make a judgment based on just what I've read rather what I've seen interstate.

MS SCOTT: All right.

MS HARRINGTON: I think it's very obvious that within Queensland there's inequity for people under our insurance model and I think that that has influenced the type of services even compensable people can access. I think there are strengths in a private model and certainly some efficiencies but I think there are also risks, and I think there are strengths in a public model but perhaps some inefficiencies as well. So I think that there needs to be a collaboration and a variety of responses.

MS SCOTT: Okay, thank you. That's a sensible answer.

MR KALISCH: Do you see some advantages in Queensland moving towards having a no-fault scheme?

MS HARRINGTON: Certainly, that's part of the reason I'm doing my PhD to see whether quality of life for people is better under a no-fault scheme and the types of services - whether they can access the services they need and also whether it's better for carers.

MR KALISCH: At this stage of your research, what are some of the advantages you see?

MS HARRINGTON: Having a no-fault model means you can access funding to purchase the services you need. There's also an entitlement that automatically comes with a no-fault model that in a common law scheme you have to actually fight for and you have to wait until your settlement before you get the money. Insurers are obliged to fund rehabilitation but they're not obliged to fund all the other things that go with accessing rehabilitation, which may be driving to another city to actually access the services you need or your family relocating to the city where the services are. Yes, I think there are certainly advantages to a no-fault model.

MR KALISCH: Just one more questions and then I'm sure Patricia has others. In terms of the issue you raised around individualised funding and the packaging and I suppose the suggestion that I thought I heard you make about trying to make sure that they were segmented or separate pockets of money for different purposes. If the individualised funding was all inclusive and properly designed, properly estimated, that it did capture all the costs for the individual and their family carer as to respite needs, would you still want that segmentation?

MS HARRINGTON: I think that there needs to be flexibility. I think there are some people who won't need family respite, for example, young people with physical disabilities, a spinal cord injury, internationally they're the people who have opted for a direct payment option because they can coordinate their care, they can access the resources they need, they can access the information they need to actually find the services they need. But for people with complex care needs, which is what is reflected in our people who are in aged care, having to try to navigate the service system and work out what you're going to spend your money on is quite complex and I think in the UK the people haven't opted for that option, they've opted to give their money to a service provider to coordinate that. I'm not sure that that is necessarily the best model. I think there needs to be a separate system of advocates to establish eligibility. We've seen the value of advocacy here. People need advocates and the person and their family need to be at the centre.

MR KALISCH: Should that be the choice of the person to be able to opt in or out of individualised funding or is that something that should be determined because of the nature of their care needs?

MS HARRINGTON: That's a very good question. I think that if there is the option that anyone could have that choice then there needs to be some sort of monitoring and a review process in place because I think that we need to look after carers really and that would be my concern that carers don't get the respite that they need and equipment is essential, it's essential for someone's independence and to protect from injury and for communication, and if that money is diverted into care, it maybe better for the person receiving care, but what about for the people who are providing care? So there are problems with that model. Obviously it's really difficult to access care and some entrepreneurial people actually get people to come from overseas and live with them and provide care. But that person doesn't have any protection if they have an injury. There's no occupational health and safety protection for that person. So cash payments have some definite risks for people.

MS SCOTT: In terms of services in regional and rural and remote areas, is there a model that works effectively or that you've seen from your research that works effectively? Is it relevant that there would be a provider of last resort or something that the government would - it may well offer in certain cases or in general cases individualised packages but it would also provide an underpinning of support in some locations.

MS HARRINGTON: Yes.

MS SCOTT: Could you talk about that? Is there anything you can offer on that?

MS HARRINGTON: Yes, I think that's why I've been very interested in also looking at the New South Wales system, particularly for people with brain injury. Their public service system is an underlying system that provides a safety, I guess, if people aren't able to access the services that they need.

MS SCOTT: You're just saying we need to follow this through.

MS HARRINGTON: Yes.

MS SCOTT: Do you want to say anything more on that?

MS HARRINGTON: The other thing I'd have to say - you'd be aware there's a report on individualised funding that's just been released in New South Wales. I think Disability Services Queensland actually said in that report that people in remote areas or rural areas have benefited from a cash payment system because there are just not the services there, so having a cash payment is useful for those people. Flexibility, I think, is really the key.

MS SCOTT: Thank you very much.

MR KALISCH: Thank you.

MS HARRINGTON: That's all right.

MS SCOTT: Can I just have indication now whether there are any people who propose to speak at the end of the day. Three, all right. We're scheduled to have afternoon tea now but because there are some people who would like to speak at the end of the day, can I ask that you be back here at 25 past 3. Thank you.

MS SCOTT: I'll resume the hearings now and welcome to the table Ben Lawson. Ben, could you just indicate whether you are speaking on behalf of yourself or an organisation and would you like to make an opening statement.

MR LAWSON: Yes, I'm speaking on behalf of myself as a person who has a long-term disability and I require multiple visits from support workers every day and the use of state-subsidised medical equipment, so my chair, my shower chair, pressure relief cushions and that sort of equipment as well as disposable-type equipment. I have been through the school system and tertiary education system and I now work full-time in the public service. Over the course of that journey I guess, as well as try to undertake all that training and work, I've also had to piece together my support system and I keep having to actively be involved in that which makes it incredibly difficult with the demands of work as well as making time in the middle of the day to try and sign all the necessary paperwork, the continual reporting requirements et cetera, so it's a real challenge.

One of the key things of my submission is obviously around the challenges of structuring a support system to ensure that people with disabilities have the greatest capacity possible to work. That's not saying everybody is going to be able to work, and I'm fortunate that I can in the current situation. But it's only there because of luck and a strong support network rather than the system accommodating that. I really support a system that is going to allow people to work and participate in the community more generally into the long term with certainty, because one of the key drivers of this that got me thinking about how we can structure a better support system is this constant issue that I face when I go to work every day and I circulate in the community and I constantly get people coming up to me out of the blue, people that I don't know from a bar of soap coming up to me and saying, "So what's wrong with you?" and if I went up to anybody else in the community and said, "So what's wrong with you?" they'd see it as a fairly confronting kind of question and I find it much the same way.

My feelings on the matter is the more people with disabilities we can get out there in the community doing things, whether that be full-time work, part-time work, voluntary work, getting out there, doing anything, going to sports days, participating in community events, the more familiarity that people have with disability the better we'll be as a community. In terms of support arrangements, as I said, I've developed those support arrangements just through continual work and trying to beaver away applying for funding, piecing together bits of support as they come to hand and also a network of advocates and people that know the system that can help me out to try and piece that together. It really is just continually chipping away at the coal face trying to get that support network in place, especially with someone like myself with changing support needs over time.

I should just make clear in terms of my submission, I'm using my example, not because I think it's a good example or whatever, but it's the only example that I can speak on, so I'm just speaking from own personal perspective rather than trying to project it to anybody else or any particular other party. Despite piecing this support network together, I still have no long-term certainty over my support. It relies on the goodwill of my service providers and continually working with them to identify issues to fix up problems, et cetera. Even though I am employed, if I was to have to fund my own support, I'd be worse off than being on the pension, so that shows there's a certain - I pay some taxes and I don't require much in the way of pension or anything like that, but there is an expectation out there or there are some people that suggest that if you work, then you should be less eligible for support.

But what I'm saying is the long-term support system, we need to bring in - we shouldn't disadvantage people with disabilities who do work because that's going to make the situation worse, not better. So narrowing it just to people without narrowing it too far will have an adverse impact as other parts of the government policy does as well. The current crisis based nature of disability support in Queensland and in other states obviously gives me little chance of obtaining extra support because of that prioritisation to people who are the most in need of critical support and so that crisis-based system just perpetuates this churning of people, giving them a little bit of support, helping them up a bit and then pulling the rug out from underneath them and dropping them back down again. So you've got this churning of support at the moment. I think one of the key things is bringing that certainty so that people can plan for the future.

The current system is poorly structured in terms of gaining long-term and meaningful employment as a state-based system has almost no connection to employment outcomes. It's entirely based on just providing support and so there's a real disconnection between that and the federal system, which obviously picks up the tab for the pension system and also employment outcomes. So there's a disconnection there, there's no incentive, as I see it, for the states to achieve better employment outcomes.

One of my key gripes with the current system is that in applying for support you're forced into the situation where it's entirely focused on what you can't do rather than what you can do. So right from moment one you're in this situation where you're trying to prove that you're the worst off of everybody in the state rather than actually saying, "With extra support I could achieve this and do this." There's no positive to this system at the moment, so we need to turn that on its head so that we start to look at better outcomes for everybody because that would create much better outcomes.

As I flagged in my submission, there's virtually no capacity to move interstate because the systems aren't in place. The states are silos that are virtually not connected so there's no capacity, even if I was offered a much better job or if my health outcomes would be better in another state, I've got no hope of moving there. I have to virtually just throw away my support system and start again and there's no way I'm going to do that.

MS SCOTT: Can I just interrupt, if that's all right, we'll make sure that you get your time. But is it as bad as you're portraying it? We had heard there's no portability of aids and appliances but I was speaking to an occupational therapist the other day and they said someone was going to Queensland from New South Wales and while that's what the official thing states, if you actually approached the state and said, "Wait a minute, this wheelchair suits me, it's got another couple of years of life in it, I want to take it," she thought you probably could negotiate because it's someone moving north. Is it as bad as your portraying it?

MR LAWSON: I made informal inquiries a couple of years ago because I was pursuing a job in Canberra and I inquired about the support system and, as I state in my submission, I was told there was a process to go through to apply to move interstate with your funding. The arrangement that is in place is, if the states agree, the state you move to is obliged to continue with your funding for one more year but then you go back into the system and you have to start from the bottom and work back up again. So it makes it virtually non-functional because 12 months is not certainty. That was my understanding at the time and I believe it's still the case. I have no evidence to suggest otherwise.

The other situation is that there are different levels of support in terms of medical equipment in different states. So, as I pointed out, I think the ACT has virtually - if you don't have access to a DSP card, you can't get access to subsidised medical equipment. My chair cost $10,000 or thereabouts. I don't have that money sitting around in a bank account just waiting to be used. My inquiries suggest that there was no certainty and it was effectively you couldn't move interstate.

MS SCOTT: Thank you.

MR LAWSON: So just summarising, I think the key issues really are early intervention for people with disabilities to make sure that people get off - as soon as their disability is recognised then early intervention can allow people to avoid that spiral and desperate situation of trying to piece together all the support and the necessary rehabilitation to maximise their opportunities. It needs certainty so people can plan for the future and they can make the best of the situation. Flexibility and minimal bureaucracy so that people can structure their care to maximise their opportunities and capacities.

In 2008 and 2009 I was part of Bill Shorten's business CEO forums as a community representative where meetings of the heads of large corporations, the big banks, a lot of the resource companies, a lot of commercial companies, and one of the key things that they pointed out was this need that they were keen to access this pool of potential employees because there's a lot of good attributes to people with disabilities, they're persistent and a lot of different things, but they found the whole system really confronting and difficult to negotiate. So for them as businesses trying to turn a profit, they found it just too complex to negotiate. They really want simplicity too. So it's not only people confronting it from my end of the situation, it's also people looking to employ people with disabilities that need that flexibility so that they can do their best in that respect as well.

I am also a very strong advocate of individualised funding as the first port of call because I think you need to tie funding to the individual and let them make that choice because without that you end up with these highly bureaucratic systems in Queensland, and I have set out some of that in my submission just how complex it is and there is so much paperwork and it's getting more so. All this talk about cutting red tape doesn't happen in the field of disability, it gets more and more complex and there is more and more funding tied up in administration rather than direct support. As I pointed out, why shouldn't I be able to choose a support provider that has minimum administration costs so I can maximise my support hours or make a choice as to what I need. I know there are some various arguments around that but I think that should really be the starting point and there are some systems that might work around that. But I think individualised funding is a really important component.

Queensland, unfortunately, is moving towards more block funding which puts the onus on support service providers to pick up people and people are at their behest as to how they structure and, as I say, there's different attributes to different service providers. I found some real difficulties with some of the larger, more bureaucratic support providers but I've got a small service provider at the moment which works really well for me and that's really important. So letting people choose is not saying there's a right answer to any situation, but let the person choose it. If they're not happy, let them move. I think that pretty much encapsulates my situation.

MS SCOTT: Thank you very much.

MR KALISCH: Ben, you talk in the notes that you provided us with about, I suppose, the way in which your family circumstance encouraged you to be forward looking, think about aspirations, go for it essentially.

MR LAWSON: Yes.

MR KALISCH: I'm just wondering about your experience with the education system, whether that was positive or whether that had particular difficulties that you'd also suggest that we should be aware of.

MR LAWSON: There are some issues there obviously with accessibility and a support provider within the education system. At the time when I went through the school system I was not so dependent on support and so that made things easier. But had I needed high-level support that would have been much more complex. I think there are some real issues there and it's really important to teach people in the education system, wherever possible, to maximise opportunities, give people chances to move on to wherever they might end up.

I grew up on the Sunshine Coast, which is about an hour north of here. I moved away from my parents to come here with my primary care providers, and that was really when my initiation into the service provider system started, because I was in Brisbane on my own without any support network. So that was where a few fortuitous meetings and whatever managed to cobble together a bit of a support network that allowed me to go through university and to be here now. That sort of continues till now.

There were some key issues at university. They provided some supports and that was important. It's a constant challenge to keep on top of everything, to manage not only your evolving circumstances as you grow up and all those kind of things but also trying to in parallel manage all these other systems. So getting drawn into all these disputes over how all these people are going to start finding new workers constantly, all that kind of thing, it all just takes time and energy, makes things difficult to move through. So the more certainty the better.

MR KALISCH: I just sort of worried about what should be a reasonable expectation, in terms of in your environment. You're articulate, you're quite well educated. How much should any scheme expect the individual to navigate some of those things and effectively make choices, as opposed to how much support should also be provided, because, as you point out, it can be unreasonable expectations of having to manage that system.

MR LAWSON: I just think there's enormous unnecessary complexities. I understand there are always going to be different streams, that you're going to presumably run equipment differently to support, things like that, but there are times when the sheer complexity of the system and having to negotiate with this service provider and that service provider over invoicing and things like that in the middle of the day while you're also trying to do your work is pretty complex and it's really unnecessary. If I could condense my service providers from two to one and bring my work-based type support into that fold so it was just a single provider rather than three different providers, that would make an enormous difference to me.

I have provided you with a diagram separately just of the sheer complexity of how all those interrelationships work. If there weren't so many interrelationships that you had to constantly keep in mind, to achieve any change to those circumstances, that would free up more time. It's one of those things I just have to do, but I think I could go a lot further and potentially get more work or get a higher-paid job if I didn't have to constantly beaver away at this whole system, trying to make it function and cobble along. So for somebody in a more difficult situation, with even higher support needs or even more changing support needs, that can often be the obstacle that just completely rules out participation or really limits people's capacity.

So the simpler we can make it I think the lower the cost and it will also achieve better outcomes for people with disabilities down the track. I think what also needs looking at - and I'm not sure what the answer is - is to bring incentive into the whole system and to maximise people's participation. If there's some way of bringing those benefits into the whole support system so that it makes for more money available, that would be a useful way.   Like, if I could bank my tax or something like that so that it then went into a support arrangement for me, then that would lessen the needs on the rest of the system, or something like that. I don't know what that answer is, I'm not an economist, but you guys are.

MR KALISCH: From your understanding of government, is part of that navigation and that bureaucracy because funding is sort of tied up in different individual programs, and so people are having to acquit and account for different funding sources; whereas if it was within sort of one overall scheme where there was the flexibility, could you envisage there being that sort of ideal situation that you're looking for?

MR LAWSON: Yes, I think because there's so many different systems: there's work-based personal assistance which is strictly tied to some limits around what it can be applied to, so it's about toileting and eating in the workplace, support during work hours, which has very strict criteria; there's personal support that has certain limitations imposed on it; there's the availability of medical equipment. There's multiple little channels of systems all over the place which requires constant piecing together, and doing so really makes it tricky. So if we can simplify that - each of those obviously has different agencies running them, whole bureaucracies set up to manage them - because there's no way of cross-linking them at the moment.

MS SCOTT: I have only got one question. Given the complexity that you've outlined for us, the fact that it's cumbersome, potentially dysfunctional, why do you then support a no-disadvantage test, because if you have that and someone particularly likes one element of a scheme or something particularly suits them and you've got a no-disadvantage test, doesn't it mean you've got to have an awful lot of grandfathering of different bits and pieces - - -

MR LAWSON: I guess when I talk about a no-disadvantage - I probably should have explained that a bit better, it was written late one night - what I mean to say is that people have a structure, a certain amount of support generally as it is. You hear rumours of people with heaps of support that don't know how to spend it all, et cetera. Wouldn't we all like to have that? But what I'm saying is we need to start off with some kind of base level to start this system.

If we're going to completely restructure the system, we can't just pull the rug out from underneath people and let their whole support network break down. I'm not saying that you should grandfather all those arrangements, but that general quantum of support would be one place to start. There's going to be complexity about that, and you guys can have a think about it, but I'll leave you that difficult one to deal with.

MS SCOTT: That's a good hospital pass. Thank you very much, Ben. Thank you also for your material.

MS SCOTT: Very good. Because we need to move through quite a few speakers this afternoon, I now call to the table Paul Hamilton, please. Paul, thank you very much for coming along and thank you for providing us with material. For the record, could you indicate whether you're representing yourself or an organisation, please.

MR HAMILTON: Yes, I'll just read through if it's okay, because I've put that all into it.

MS SCOTT: Yes.

MR HAMILTON: Hello, ladies and gentlemen. My name is Paul Hamilton and I asked if I could come here today and speak. I am not employed by any organisation nor am I a member of any volunteer group within the disability sector. I also do not have any degrees or training in any of the many professions of work within the disability arena. That sums up pretty much what I'm not. My girlfriend might have a longer list, but for the purpose of this inquiry that should cover it.

As far as my credentials go, I rolled through the door. Before my car accident I worked as a mechanic and was involved in contract orchard work, and my highest level of education was early high school, year 9. I have also travelled extensively in third world countries, mostly east Asia. My initial injury was the crushing of my C5-C6 vertebrae and damage to my spinal cord at that level. They stabilised my neck with surgery entailing a bone graft and rods. I was diagnosed as a complete quadriplegic. This meant that I had very little movement of feeling from the shoulders down, and the prospect for recovery was fairly bleak.

I spent 16 months in the Princess Alexandra spinal cord injuries unit. During this period I utilised all of the hospital services and for the first nine months made a far better than expected recovery. Due to a loss of regained function, I discovered that I had a cyst in my spinal canal, so more surgery, seven months a couple of spinal plural shunts later I was ready to re-enter the world. A steep learning curve. As I had no family and I was a fair bit of a loner, I had no real outside support advocating for me, in the way of people in my life before my accident. This can cause you to fall between the cracks that exist within the hospital system. To avoid this, I took control of my own recovery and advocated vigorously for myself.

A new Queensland based fund, SCIR, Spinal Cord Injury Response, had only just been started and through this I was able to get a large number of my initial needs fully funded. I must stress, it took a lot of effort and stress while also trying to rehabilitate. If you come into the world of disability via a traumatic injury through a hospital it's essential to your future, being disabled long-term, that all your initial needs are addressed and met during your rehabilitation and leading up to being discharged. For a traumatic injury long-term disability, that is one of your points of early intervention and also assessment of needs.

As return back into the world very much commences within the hospital environment, it is essential to your being able to orientate yourself towards a useful life in the community living with your disability. A Blue Care nurse I know who has 20 years nursing experience, who has worked in the community with the disabled for four years, believes that a case worker assigned to manage a long-term overall plan, two years or more, with a client is required to effectively follow through with continual integration the community after discharge.

This fits in with my own experiences, as my first two years after discharge were the most hectic. I privately rented for the first 12 months and then lived in my girlfriend's mother's garage for another six before being able to get state housing. The biggest problem I had accessing services, and which almost everyone else complains about, was finding out what the services were and what my entitlements were under that service.

There needs to be under the new system some sort of one-stop government shop that has answers to all questions that apply to disability services within Australia, and if it does not have answers to questions posed, it needs a clear-cut and expedient mechanism that researches and applies processes to find an answer and resolve the problem. So in that way it progressively grows in its effectiveness. In fact the whole system would have to possess a fluid, evolutionary nature to stay abreast of changes in disability that happened on a daily basis.

As to the question of how to determine eligibility, this would have to be carefully decided by dedicated medical professionals. In my own experience, I was well on my way up, until nine months into my recovery, to all but complete self-care. But after I developed the cyst everything changed rapidly. I now have a high level of support and care needs and a continually fluctuating level of function. I would not have qualified for a high-care support package one day; the next, literally, after major emergency surgery, I did.

Also, early intervention needs to be a main credo or theme of the new system. Early resolution of any emergency or problem or lifestyle implementation in a disabled person's life avoids suffering and complications and avoids unnecessary burdening of other services. Since leaving the spinal unit I have had a number of people find me who are in similar circumstances to what I was, where they had no family or strong external advocates to keep the impetus and focus on a properly implemented and encompassing recovery plan, so I assisted these people as best I could, helping to explain and direct them towards the services I found and utilised.

Where the ideas of work come into play, to me, seems to be the area that is least explored within disability. It has potential for the greatest area of expansion and innovation. One idea that I have explored with other wheelchair-dependent disabled people is the potential for a business based on advertising from wheelchairs. The wheels and back of the manual and power wheelchairs could be adapted to carry an advertising message. Some people will gasp that this is the commercial abuse of disabled, but not if we the disabled think it's a good idea.

My concept is people already look at the disabled in wheelchairs. Why not give them something to look at. Imagine, what could be a more perfect vehicle for government safety awareness message. A company could form around this concept, run and managed by disabled themselves from computers at home or a suitable work environment. You could have individual contracts that allow the participants to advertise to the extent that they top up their pension to the allowed amount that does not affect their benefits. Down the track a business template could be developed that could be sold as a franchise-type business to other countries.

Another idea was online call centre and help site work. Rather than work going in this area overseas, we could access and train interested parties who could then work from home. I even thought of converting my power chair into a mobile entertainment business, founding a company called Quadraphonic Rockers. Radical ideas. I'm a quad in a chair, and I would interested and so would many others. This could also later feed into the other question of where the finance could be found to support the new system.

Made with great thought, planning and inclusion of all concerned parties in the process, there might be found a way to see a day where disability is no longer a barrier for people to develop ideas and earn a living, a day where this sector's unique assets are no longer a drain on social services but a vibrant and growing new area of industry that can support its own limitations by utilising so far unused assets. I am a man of dreams and an idealist. The only way to ever truly turn all of this around and bring in true change is some totally different approaches. Adversity is the mother of invention, and I have seen some amazing ideas and inventions spring from the impetus provided by coping with disability.

Again, early intervention, as the main common theme within the system, applies to work productivity, can help with health and a sense of wellbeing, not to mention benefits of improved lifestyle and social inclusion. The entire time out of hospital since my accident I have studied and worked from home towards re-entering the workforce. It is crucial to me for my sense of usefulness and self-worth. I have had a long and difficult recovery, which is still ongoing. The final result of my struggle is still unclear. Working and learning helps me feel I'm doing more than just surviving. I have helped a dozen other people from the spinal unit enrol with the same online course that I found through the pensioner education scheme and they almost all have expressed the same sentiments.

Another question that was asked in this issues paper, "What could be done to avoid or reduce the impact of any unintended consequences?" Again, early intervention, coupled with a hotline where at the end of the phone line or email you get answers and action; a crack support team that can quickly address any issues or problems that arise through the rollover to new services, a part of their training being the very essence that this is a difficult and very problematic issue that will require innovation, patience and understanding to accomplish.

Just as people who are presenting here to your commission are taking on good faith that this is all being done for the right reasons, contrary to an awful lot of previous experiences, so too will the new system and its administrators need to believe that all problems and complaints that will occur come from a genuine need and will have to be properly assessed on a case-by-case basis, no more pigeonholing of people's issues, end the labelling and buck-passing. I gather that to do all that you would need to do you would have to overlap your new services whilst absorbing or utilising existing services, identifying and gathering information to find the best practices and then phase out overlap and then govern and coordinate from the one organised main body.

During this process everyone will need to embrace mistakes so as to learn and find solutions so everything continues to move forward. You will need to absorb existing providers and organisations, workforces and staff into the new system, to meet needs and preserve knowledge and experience, perhaps a broader, alternate and prior learning equivalency system that gives legitimacy and employment opportunities within the new system that allows people with large bodies of experience without formal learning to be utilised. These people have highly developed problem-solving skills within these areas as they have had no choice but to find a way in the past. They have been dealing with the problems for years, they will help guide the whole process in part towards a solution. We can avoid many pitfalls if we don't forget about what we already know, also look at ideas of the disabled themselves, our unique perspective and adversity coupled together and often we have the answer our own problems, we just need assistance.

The question, "Can you foresee any unintended consequences from the introduction of a disability carer support scheme?" The short answer is, hell, yes. The longer answer: you'll encounter problems such a gentleman who owns a disability solutions company that installs, amongst other things, hand controls for cars. His worried voice to me is, if the funding rules are federally based but the road rules are state-governed, who knows what will happen? I notice that your issues paper repeatedly mentioned the overlap of services where identification of this under the new system could result in streamlining and potential savings. We'd have to be aware and guard against leaning too far towards financial gains and lose sight of what truly is trying to be achieved. Also the sporadic and unplanned way the current system has sprung up on needs and individual efforts basis has created a fragile web that quite often works to your advantage.

A case in hand is a man I know who required a power wheelchair. He failed to get his needs met in this area while rehabilitating and when he was released from hospital the transitional program, TRP, helping him to get back into the community also wasn't able to help him. Even a long-term spinal program was unable to get him one, nor the spinal groups that exist here in Queensland. He was in danger of falls and further injuries, then he contact Community Health in Aspley and they were able to find him the funding. If there was only system and it was too inflexible, this person may become an unnecessary drain on the system through preventable problems.

The system that exists, though, with the serious problems has also saved my life repeatedly and though it was not easy or clear-cut has enabled me to get a lot of equipment that was vital to my last four years of disability, but I have to stress that I had life experiences that prepared me for all of this long before. A very long story. Something that highlighted serious concerns recently was the historically fickle times in government recently with the leadership change forcing an early election. Whatever is decided to be implemented on a national basis has to be free from effect from political change. This is a national issue, not a political party issue. Whatever is started must be followed through on. We cannot run the risk of being caught mid-systems. More people will suffer if this is messed up.

You will have to sweep away old doctrines of blame and denial, instead opting for acknowledgment and resolutions. You will also have to have clear ways to measure government department effectiveness and work output. You also have to be able to sack people who clearly have shown they don't suit or achieve the aims of their position. Also a real line drawn between administrative costs and end outcomes, we need to have fair competition in prices of services and equipment. The government needs to start getting value for their money. Also please remember there is a huge body of people you're unable to hear. They are the people whose everyday life is taken up just by surviving. They are the people who are really suffering. This is not a job for the faint-hearted. Equally, it is a job for only those who are dedicated, as dedicated as those who carry the burden of the actual disability and their families.

In conclusion, please remember that the definition of insanity is doing the same thing over and over again and expecting a different result. Also intelligence is not measured by the amount you have learnt or know, but the application of that knowledge. Two things I've learned over my recovery: if you're not trying you're dying, but if you're not learning you're already dead. Thank you for allowing me to speak here today.

MS SCOTT: Thank you very much. Thank you, Paul. Are you comfortable if we ask you a few questions?

MR HAMILTON: I'm glad that you guys were okay with letting me get right through that.

MR KALISCH: I just wanted to ask about the once-off government services that you talked about. What sort of range of services do you imagine that would coordinate and provide people with?

MR HAMILTON: Everything that comes under whatever portfolio your new system is going to cover. If somebody is covered under your new system, you need to have the answers at the end of a phone that can address the problems or you need to have something in place that can sort it out. The greatest problem there is finding out what's available, it really, really is. It's the best kept secret since Atlantis, seriously. When I talked about pigeonholing, I think that a lot of services are overtaxed and some ways that they find to deal with that is that they will pigeonhole somebody and say, "They're depressed," or "They're not dealing with their injury," and so on and they can move quickly onto the other people they can deal with and then utilise their services to the best advantage, but then the pigeonholed person then needs to be picked up by the next or the next service provider down the line. There are still people who aren't being picked up all the way down the line and they fall right between the gaps. The answer is everything, it has to cover everything that it's going to be trying to govern.

MR KALISCH: So in terms of any new scheme, should there be, I suppose, that sort of information service essentially, in effect a 13 number or something like that?

MR HAMILTON: One of the ideas that some of us guys were floating around - I've been a 20-year member of Alcoholics Anonymous and I've been Narcotics Anonymous as well - the way that group is structured is they spring on a needs-by-needs basis in local areas and they're supported by the bigger shell. This is such a big problem, not being able to get this information, I thought of creating a form of Disabilities Anonymous - a bit of a pun because rarely are disabilities anonymous anyway - but a place where people could come, you could talk about problems and you would have a database there that you just fed more and more information into. People could spring these up locally, they could run from the back of little churches with a dollar coin donation. Something like that could still start up with the new system being rolled in and be firmly integrated with it.

The people who have the greatest investment in everything you're about to take on are the people who are provided by what you're about to take on. If you guys don't find a way, we will eventually one way or another because it's not by choice.

MS SCOTT: Paul, you've put forward a number of interesting entrepreneurial ideas but you've also said you were interested in going into work yourself. What are the barriers you face to getting into work and would you expect a national disability care and support scheme would directly assist you and what would that assistance look like?

MR HAMILTON: That's a big question. Pretty much the way I've been motivating towards getting back into the workforce for myself has been to work from home. I've got some fairly complicated medical issues that all interact on each other and to be honest I don't think you could really come up with a way to get me into work on a regular basis reliably. So I've been doing online computer courses, I build and repair computer systems, I repair laptops. I got into laptops because they're fiddlier and they challenged my hand function. So it's not something that I've really looked at because I'm going in a direction where I'm going to start my own company, own business and provide my own work needs anyway.

MS SCOTT: Okay.

MR HAMILTON: That's a question for people, like the gentleman who spoke before me, who's got a greater idea of what's going on out there.

MS SCOTT: Okay, good thinking.

MR KALISCH: I'm done. Thanks very much.

MR HAMILTON: No worries. Thanks again. By the way, you guys have got my email at the bottom.

MS SCOTT: Yes.

MR HAMILTON: If you want any more answers, just give me an email.

MS SCOTT: Thank you.

MS SCOTT: Good afternoon and welcome to our hearing today. Can I ask you to state your name and if you're representing an organisation and then you might want to start with an opening statement. Thank you.

MR ARMSTRONG: Yes, that's fine.

MS SWIFT (KCA): Sure. My name Karin Swift and I'm a project worker with Kyabra Community Association.

MR ARMSTRONG (KCA): My name is Matthew Armstrong and I'm also a project worker with Kyabra Community Association.

MS SCOTT: Matthew, you've got a bit competition with the traffic outside, if you could talk up a little bit more.

MR ARMSTRONG (KCA): Yes, so my name's Matthew Armstrong and I'm also a project worker with Karin with Kyabra Community Association. Karin and I have been working on a bit of a presentation about our work and the work at Kyabra Community Association and so we welcome this opportunity to present at the hearing of the Productivity Commission on disability care and support scheme. The presentation will support many points raised in the issues paper and highlight some of our key experiences of working inclusively with people with disabilities and their families.

MS SWIFT (KCA): I just wanted to take a few moments, if I could, to address a few points in the issues paper that we particularly agree with and we acknowledge that it's fundamental for each of these key points to be included in any scheme. So the first is the need for flexibility of funding and we believe the support provided to people with disability needs to be portable to provide flexible lifestyles for people with disabilities, like any other citizen. So it should be able to be spent flexibly and attached to the individual rather than the service and that that could be across a number of things, for example, specialist disability supports or even generic services, like if a person requires a house cleaner to help them keep their home tidy, then that's what they should be able to get in.

We also feel that people with disabilities and their families should be encouraged as much as possible to design their own services and their own housing and their own communities. We also support the importance of access to early intervention services and we feel that timely, seamless and services that offer practical advice and support is fundamental to anyone in the early stages of having a disability, whether that be parents of young children or people who acquire disabilities later in life. We also support the importance of supporting people's participation within the community. People with disabilities should be supported to take their rightful place as active participating members of society. So this means they're supported to participate in all social, political, spiritual and cultural aspects of life.

Funding under such a scheme should be seen as an entitlement. We really support this and it's important that equipment and reliable support be seen as an entitlement, not something that families have to barter for or apply for and be rejected or constantly negotiate. We also support obviously the need for a sustainable model of funding and one of the ways we think this could be is that if people are - it needs to change its thinking so that people don't always think they have to apply and receive a disability service. So if what they need is a meal once or twice a week, then they can actually go and buy that from the local restaurant, which might be actually much cheaper and more sustainable than getting it through a disability service.

Most importantly, Kyabra believes in the importance of appropriate support during transition periods. Kyabra supports the idea of lump sum payments being made available to people in periods of transition so they can buy the goods and services they need or make investments around particular life stages. An example of this would be a lump sum payment being made to a young person who is about to move out of the family home so they can pay for any home modifications necessary or buy the support they need to live independently.

I just want to briefly touch on just a few barriers and obstacles that people currently experience and that's access to appropriate informal and formal supports. Through the current funding system many people get no support at all and people's informal supports are pushed to the absolute limit and I'm sure you've heard some examples today of people sharing their stories and many people ending up in crisis situations. Then a big one we find at Kyabra is people's access to affordable and accessible housing, and we identified a number of barriers that may arise once people secure funding for accommodation and support and they include some people not already having a house to live in, and with appropriate affordable housing being in short supply, finding a place to live can be a real barrier to people's future plans, the Department of Housing not being readily available to people.

In Queensland in recent years there's been a shift away from a wait-turn system to housing people in the highest crisis, like homelessness, so that means that people who are in the family home and just wanting to make that transition to community life can't because they're not seen as in urgent housing need, they're living with their families and then that plays out to people being in situations of crisis when their formal support can't meet their need any more. Then we also feel there are barriers around connection, belonging and actual citizenship in the community as it requires flexibility of funds at an individual entitlement level.

Now, I might just get Matt to talk about some of our work that we've been involved in, specifically with Building Tomorrows Together and the living-in project.

MR ARMSTRONG (KCA): Initially I provided support with one family who has a son with a physical disability who wanted to move out of the family home. I was part of the BTT project. We explored the future vision of the family and explored the different living situation scenarios that that young person may be able to move into, and then, after arranging some independent facilitation, some of the family identified two potential flatmates that he would be interested in sharing with, and consequently, one family and their adult son made contact with that particular family and expressed an interest that because of their son's friendship over eight years that they would be interested in sharing together.

A house through the living-in project, which is part of Kyabra's social enterprise unit, was being built at the time, so it hadn't been finished and was consequently offered to both men. Both families expressed an interest to explore the possibility to move into this house and to be involved in the fitout and the modifications of the house, to personalise it and make it their own place. The downstairs part of the house utilises principles of universal design and is completely independent and accessible from the upstairs part of the house, and there's an internal stairwell between both parts, with the upstairs part being like a renovated colonial cottage.

The BTT project has supported both men to trial living together in accessible holiday units on the Gold Coast, and in this scenario we were able to help both men explore issues around capability, sharing a living space, socialising together, doing the shopping, doing some food preparation, looking at paying for the bills and the cost of that accommodation, living independently and looking at the budgeting side aspect of being on a Disability Support Pension. This was funded through the CRCC, Commonwealth Respite and Carelink Centres, the funding body. In the next couple of weeks it's looking at having someone - to the knowledge of both blokes - to just review it, so it's quite independent from Karin or I, to sort of get more of a sense of how that went for them.

In addition, BTT has been working with the men to increase their connection within their community, accessing the local shops from the actual house, even though they haven't moved into the house, and we have been looking at the accessibility aspect of getting to the train line, looking at contacting the local council to put paths - one of the blokes I work with has a scooter, so we needed to sort of identify that as well - and just a general orientation around the train station, accessing lifts and things like that, and the help station, areas that have recordings of trains that are coming on and that.

Then also just looking at fire safety as well within the house, looking at the items that they would need to look at purchasing and trying to develop a bit of a list. That has been probably over the last three months. Both of these blokes have applied for the community living initiative and need this funding to move in. The situation is the house now is finished; however, no lease has been signed because of the funding, the funding hasn't come through yet. So I guess our project is negotiating the whole plan of the place, because it has been set up the way that they want it to be set up, and so we're in that process at the moment, and getting support to do that.

A couple of issues, as a worker in that process and spending time with the family over the last six months. Issues with one of the men's parents, who are aged mid-70s. Found, for example, even though the community living initiative is on the right track with developing community connections and informal support, they were a bit more out of the loop as far as the language and how to fill out the forms, from a system which is more traditional, with applying for funding.

Also, with the focus of the plan having extensive use of the likely informal supports, they had had a lot of paid supports coming in, so that part of it, even though that's sort of developing now and it's making that connection with community a lot more now with support, that hadn't really been part of their life. So that was quite a different aspect of it. Again the issue comes down to both families being entitled to apply for the funding, whereas the funding needed really to be as an automatic entitlement, and therefore they could just move into the house when they're ready. It's all that transition work sort of coming along.

The time of anxiety around the parents letting go and making that sort of move and making that sort of move with their sons is more magnified by the funding uncertainty as the plans and the safeguards that they have been working on are now collectively as two different families coming together and working through setting up this house, there's sort of the element in the back of their minds, "We're putting all these things, but we haven't got the money yet."

So rather than it being like, you know, "Things are going really well," and "Let's do a gradual move-in next week," because you feel ready, or maybe one of you feels ready to move in downstairs, and then one maybe come over, that could take six months, it's more solely exclusively dependent on the funding. So that sort of anxiety magnifies that whole thing of making that step for the family.

MS SCOTT: Matthew, I'm sorry to interrupt, but why is there uncertainty about the funding?

MR ARMSTRONG (KCA): Well, we just haven't heard - - -

MS SWIFT (KCA): We just haven't heard if they have been successful.

MR ARMSTRONG (KCA): - - - from the funding.

MS SCOTT: So you have gone down this path in anticipation that you're going to get the funding?

MR ARMSTRONG (KCA): Yes.

MS SCOTT: So there could be two really disappointed people if it turns out you don't get the funding.

MS SWIFT (KCA): Yes, quite possibly.

MR ARMSTRONG (KCA): Yes, quite possibly. So it's just applying for that. I guess it's moving in that direction, because they have identified the relationship between the two parties and they have identified that they want to live together. So that's part of it, so it's moving that in that direction.

MS SCOTT: Are you comfortable with us asking questions.

MR ARMSTRONG (KCA): Yes.

MS SWIFT (KCA): I just wanted to briefly mention that what has been successful is that Kyabra has been able to work in partnership with families around future planning and support for the Building Tomorrows Together project and have been able to involve individuals and their families in the design process of new homes through the living-in project. Just for the panel, I have got some glossary information here about the living-in project that you're welcome to have.

MS SCOTT: Thank you.

MS SWIFT (KCA): The level of participation is not typical for many people with disabilities and their families and provides an example of the type of developmental partnership that can exist under the scheme that's being proposed. So just to conclude with a few points. Experience from both BTT and the living-in project indicates that under a national insurance-type scheme individuals would require access to additional resources, including lump sum payments at particular transition periods, particularly during the transition to living in their own accommodation. Such lump sum payments could be used for capital costs such as housing modifications and would allow for universal design principles to be applied.

Kyabra's model would allow for a person to be at the centre of the process with regards to input and decision-making and for design processes to cater for their current and future needs. With regard to the sustainability of the funding model, it will be important to ensure that individuals and their families experience some security of funding and can plan appropriately for the future. In the current system people don't plan for the future until a crisis point; for example, health issues and ageing carers and such things. So that probably brings to a conclusion what we wanted to share.

MS SCOTT: Thanks very much. David?

MR KALISCH: Yes. There are two things I wanted to investigate. One is to understand a bit more the process by which you try and help people understand whether they're going to be compatible living together in that sort of trial arrangement and the other support that happens at the start.

MR ARMSTRONG (KCA): Yes, I guess it was pretty well much like trialling - yes, they had spent that time together as friends. They were spending social time together while they were away. I guess the main thing with that was looking out for each other as well. So rather than the practical sides of the support or whatever, it's more like that thing of looking out for each other.

MS SWIFT (KCA): At all times it's fairly developmental. People make choices. Some people that we work with have decided they want to live alone. Some people have decided they want to live with people and in this case one of the men identified the other guy and said, "I've had a bit of a friendship with him over the years, we've gone to the same day service, maybe they'd be interested," and it was just a continual negotiation. It wasn't just that we came along and went, "These guys look like - - -"

MR ARMSTRONG (KCA): It started off being an individual process for that particular family and then by invitation, so it was just exploring that.

MS SWIFT (KCA): So we were able to link in with another agency that provided some funding for the weekend away.

MR ARMSTRONG (KCA): Yes, and then arranging someone independent from us to follow up and get a bit of a feel for that situation.

MR KALISCH: Can I just ask about that independent person or organisation. Do you see that as critical for getting greater objectivity?

MS SWIFT (KCA): Absolutely.

MR ARMSTRONG (KCA): Yes, to me it would go just hand in hand rather than having one person be involved in that process and get a good feeling about that, the blokes are looking out for each other and coming away with just that one opinion.

MS SWIFT (KCA): I guess it also safeguards the organisation against potential conflict of interest. There's that broader stuff as well.

MR KALISCH: Can I just ask one more question. At what stage can people say, "No, I've changed my mind." If it's individualised housing - - -

MR ARMSTRONG (KCA):   Exactly, and that's been part of that. So in this particular situation that house is two separate places and that's why it was exploring those options of that particular living initiative because it's separate and separate funding from each other and so it wouldn't be relied upon both lots of funding being joined together in one particular place. If it meant, as for you and I, or whatever situation, our circumstances change and we want to move or things are not going down that path, we'd like to try something different, that was how, I guess, that developed from that situation because it wasn't just one house that was - - -

MR KALISCH: It wasn't totally integrated.

MR ARMSTRONG (KCA):   Exactly. That was part of the reason why applying for particular lot of funding was because it supported - - -

MS SWIFT (KCA):   We're trying to set it up in a way that it's sustainable for everybody so that if things go wrong down the track or whatever that it's not a great loss for either party and I think that's one important thing that a scheme could be. If things were like an entitlement, you wouldn't have to package things up so that people are forced to co-tenant.

MS SCOTT: I've got a question that I think may be first directed to you, Karin. It's a difficult question and that is where the scheme stops because you mentioned a sensible idea, which is if someone needs to have two meals a week, why do they have to be delivered by specialist services when a restaurant specialises in that already. I've got that in my head and I think that's a good idea. I encountered someone in Melbourne who explained that their time out, their respite, is actually that they go to a movie, there's a little bit of therapy in that involving a resource of the community but there's nothing extra special, it's just a movie down at the picture theatre, so we've got that too. But then that could be everything at the end of the day. You mentioned cleaning services - so what distinguishes the lifetime care and support scheme from the rest of the universe?

MS SWIFT (KCA):   I think that's the potential beauty of the scheme and I speak for myself here. I think that it's about challenging the system to think it's not about propping up services, it's about propping up individuals and to do whatever it takes. If that's about providing someone with a bit of respite to go to a movie or if that's about enabling someone to get their carpets cleaned by a professional cleaner, then isn't that a far better use of resources than relying on the traditional human service that has a very traditional model and a traditional understanding of their role.

MS SCOTT: Okay. But let's just then test this. Someone's getting an income, let's say, and they're also eligible for the scheme because they've been assessed as needing certain services, say, they get an individual funding package so money is given to them and then they can spend it as they wish, with some accountability, but not too over the top. Someone might say, "Yes, but they're spending their money on what a person without disabilities would spend their money on." Is that right?

MS SWIFT (KCA): I think it's about providing the best possible option and you might find that a house cleaner is better than a personal carer because then the personal carer can get on with things that they don't have time to do because they're too busy cleaning the house. Do you know what I mean?

MS SCOTT: Yes.

MS SWIFT (KCA): An example that's come up in my life - it's a personal example, nothing to do with Kyabra - is that I develop a pressure sore on my leg and perhaps it would have healed more quickly if my support worker was able to pay due attention to that rather than be concerned about my floors. Do you know what I mean? It's just about providing the flexibility.

MS SCOTT: All right, that's good. That's answered my question. Thank you very much, Karin. Thanks, Matthew.

MR KALISCH: Thank you.

MR ARMSTRONG (KCA): Thank you very much.

MS SWIFT (KCA): Thank you. Please take these.

MS SCOTT: Thank you. I think Gustav is next and then we will try and do the five-minute slots after that.

MS SCOTT: Gustav, welcome to the table and thank you for providing some material in advance. Would you just like to identify the organisation you represent, please.

MR GEBELS (NEDA): Gustav Gebels, I represent NEDA, the National Ethnic Disability Association. Before I go into that, I'd like to let you know a little bit about myself. Starting off, I'm of Baltic-German origin, I've been in Australia since 1950. In 1951-52 I have brain operations. I had a cerebral abscess above my left ear. I was pretty successful after the operation, I went to university, I did four languages at high school so the speech part didn't bother me. Shortly before the completion of my degree in applied psychology in the clinical field I had an epileptic attack because of the original five operations. My last occupation in Australia was as a psychology tutor at Sydney University. After that I was offered three positions at the 12th International Rehabilitation Congress held in Sydney. The positions I was offered in Germany, three positions, as rehabilitation psychologist.

I found it quite interesting there. In some things they are quite advanced and in one of the centres I worked with paraplegics and quadriplegics. I learnt the real name is tetraplegics, the medical term, because it comes from the Greek para and tetra.

MS SCOTT: Yes.

MR GEBELS (NEDA): But the centre also had a subcentre for 137 teenagers with all forms of disabilities except deaf and blind. What Henk said before about "how about me?" I can also give an example. She would have been about 14 years old, she really looked beautiful. I didn't realise the problem at first, that she had her hands on my shoulders and her the feet at the end of her body, she didn't have any legs. But she was really happy, she learnt to be happy. One of the main causes at the centre was not only for disabled people to get to know non-disabled people, but vice versa which was very important. I don't know to what extent this exists in Australia, something of that nature, high schools with a lot of disabled people but I think it should be done if nothing has been done yet.

I returned to Australia to start the idea of Disabled People International - I don't know if you know of that. I brought it to Australia in 1981, the Disabled Peoples International was founded in Singapore in 1981 on 3 December but I managed to get a few people from Australia but 42 countries started this idea and found Australia was the only one which didn't. It was there but nobody seemed to show interest. After this I looked for work in Sydney. I obtained half a year Sydney University in research but it was only half a year and in 1983 I had to look for work and I was successful in obtaining a position as, I think they called it clerical assistant grade 1, with the Taxation Department. I had to stay there for two years because one of my jobs was to educate some other acting assistant grade 1s to do the work of assistant grade 1s and they had a chance of obtaining a better position and I was the person who was there to train them. It wasn't until 1984 that I was able to obtain a position with the Commonwealth Education Department and I stayed with them, which later partly became Centrelink.

I was well able to work there and to do my job but I think due to my disability I remained a base grade clerk - I don't know what they called it - administrative officer sounded a bit better. In the 1990s I was retrenched and I don't really know why, it might have been my disability or my disability in working but since then I've had quite a lot of difficulties finding jobs because whenever I mentioned my disability, and I always made sure I did with every application because I also thought it might be interesting to see what the people would do, if they would give me a chance or not, the consequences weren't always the best.

I helped start the MDAA - this is one problem now, I can't think of it - the Multicultural Disability Advocacy Association in Sydney and then came to Brisbane and helped start the AMPARO organisation. Actually two years ago I noticed an after-effect of the operations which I had 58 years, a bit of bone protruding from where I had been drilled when I was eight years old and it didn't stop growing so I went to have it cut off or sawn off and the first two operations were unsuccessful so I had to go to some other specialist who had quite a good success. The first specialist noticed the bone was dying, so he had to get rid of the dying bone. The second operation was to take part of my wrist here and to stick it onto here. You can still a bit of wrist on here. But I can say now, as a result, to this and to the other things you can always think to yourself or even say it, "He has a hole in the head," or "He might have a hole in the head," because that's so at the moment. So this is a bit of an introduction and I hope I haven't taken too long because this is one other thing, not only can I manipulate the speech but also vice versa and I'm on tablets constantly so that can slow me down.

There are at least one million people from non-English speaking background with disability in Australia and with family and parents this increases constantly. They all form a significant and valuable part of our community. I would like to mention NEDA to introduce us to organisations, communities and others. I would be grateful if you would pass this onto others. NEDA is funded by the government Department of Families, Housing, Community and Services and Indigenous Affairs - I don't know, is it still called that now?

MS SCOTT: It still is, as of this week.

MR GEBELS (NEDA): To provide policy advice to the Australian government and other agencies and national issues affecting people from non-English speaking background with disability, their families and carers. NEDA actively promotes equal participation of immigrants of recent or longer times of non-English speaking background in as many aspects of society as possible and full acceptance by the community. It manages a wide range of projects relating to such persons and works closely with its state and territory members to ensure that its policy advice reflects the experiences of such people with disabilities, their families and carers.

NEDA undertakes development work to establish a structure that can support disabled people from non-English speaking backgrounds, their families and carers. The question, "What is disability?" is not always easy to define and most people straightaway think - and I hope you can excuse me sometimes - of wheelchairs if they hear "disabled". A long time ago they didn't have the word "disabled" they had the word "handicapped" and mostly in that time everybody thought of a limp or a stick or something like poliomyelitis in the leg. The words have changed but the problems were still there.

One of the best definitions which I have found which was made at the world congress last April was "long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder full and effective participation in society on an equal basis with others". All forms of disability exist on NEDA's level. It does not consider one or another type of disability, as very many other organisations do, not that such are not very helpful and necessary. Yet NEDA looks at all, often with different types and forms of disability being interwoven and all from a non-English speaking background. It should be noted that all other counsellors have also originally immigrated to Australia and have some disability and can understand others with disabilities better. Past immigrants can understand present immigrants much better in many cases and I think many disabled people can also understand disabled people much better too. Disabled people as immigrants who have been here for a longer time and been able to cope with the problems here, they could be better people to make it clear to newcomers, to new immigrants who have disabilities.

MS SCOTT: Gustav, would you mind if we asked you a few questions and we might draw out your views and the views of NEDA about the future scheme? Would that be all right?

MR GEBELS (NEDA): I'll try.

MS SCOTT: We've got your material.

MR GEBELS (NEDA): Yes, I've tried to change off a little bit from that.

MS SCOTT: That was good, that was useful. Thinking about the scheme into the future, one of the questions we've asked is, who should be eligible and you've given a very good definition about disability here. Some people have raised with us whether people with mental illness should be in the group.

MR GEBELS (NEDA): Did I mention that? I mentioned mental, didn't I? I mentioned four different - "a long-term physical, mental, intellectual and sensory impairment".

MS SCOTT: Thinking about mental illness, we've got some conditions which are short-term - like, a lot people face depression. I think the figures are something like one in four Australians at some time in their life have a period of depression and so on.

MR GEBELS (NEDA): Yes.

MS SCOTT: Other times people might have conditions which are episodic or not manifest for a long period of time. In our issues paper we were seeking people's views on whether episodic conditions should be part of the scheme - - -

MR GEBELS (NEDA): I think they should be.

MS SCOTT: Okay, good. What about the level of assistance someone should be able to rely upon, even if it's the case that for all intents and purposes life is going well at the moment and they're not really facing any immediate difficulties as a result of an episodic condition. What would you like to see for someone - - -

MR GEBELS (NEDA): It depends on the type. I mean, it can be very loose and - - -

MS SCOTT: But let's say someone - in some schemes you have a fall-back system, if something happens you can fall back on the system. Others could be that you're always eligible but you come in and have an assessment or you have to wait three months; it has to have a certain level of severity before you warrant entry into the scheme. There are all sorts of different models around the world - - -

MR GEBELS (NEDA): I think this is the problem. How can you solve it? You have to see what others do, perhaps even get together with other countries and see what other countries do. This was the main idea, for example, of the Disabled Peoples International organisation, which exists on a world basis which comes together regularly but which is not from the government. They would try to make it a government idea. I think it varies, but it's definitely necessary, I think.

MR KALISCH: Can I just ask a question?

MR GEBELS (NEDA): Yes, go on.

MR KALISCH: You talked in your opening comments about the difficulties that you faced getting work, particularly, as you thought, partly attributed by your disability. I just wondering whether you could give us any indication of what sort of assistance you think might have been helpful in your case.

MR GEBELS (NEDA):   I think one problem is I was given the wrong type of tablets by a neurologist about seven years ago and that made it even worse. For example, I was put onto different tablets. I was practically poisoned, I was in hospital. For example, since then I've been put onto different tablets again which make me - I mentioned before sometimes I cannot think at all, there is a bit of a blank. It could be only nervousness but, for example, since then I've got a tremor in the left arm. I don't know why that is but I was hospitalised in the Gold Coast Hospital for 10 days before I came out of the problem.

MR KALISCH: Do you think there are some strategies such as encouraging employers to be more understanding or part-time work? What other dimensions could be encouraged.

MR GEBELS (NEDA):   I mention something like this later because this is one problem and I think it has been mentioned quite often today the problems with being employed. I might mention some of these things later on. But possibly if I try and finish this and you can ask me questions later on because I might cover them.

MS SCOTT: Maybe what we should do is give you another five minutes, Gustav, because both David and I haven't had a chance to read this.

MR GEBELS (NEDA):   Do you think you can tell me if this is approximately same and - - -

MS SCOTT: I have to say the first page I think is largely the same as what you've read out.

MR GEBELS (NEDA):   I mentioned that all forms of disability exists at NEDA's level, it does not consider one or another type of disability as many other organisations do - sorry, I mentioned that already.

MS SCOTT: I think you're up to examples of past active work by NEDA.

MR GEBELS (NEDA):   Did I mention some examples of active work which NEDA has performed?

MS SCOTT: That's the bit where you're up to.

MR GEBELS (NEDA):   Yes. For example, there exists frequent communications with other people and organisations currently taken up by a larger extent with various media such as Link disability magazine. I don't know if you know of that from South Australia.

MS SCOTT: No.

MR GEBELS (NEDA):   That's a very good magazine. One of the persons who came to Singapore for the foundation of Disabled Peoples International he printed that or he started this idea and it's a very good magazine and it comes out monthly or bimonthly. The Multicultural Mental Health Australia Synergy magazine and FECCA, Federal Ethnic Community Council of Australia, Mosaic magazine. Key issues recently discussed included topics such as ageing at home - which Queensland is well ahead of many other states - ageing at residential nursing home facilities and language problems. For example, one case a neighbour of mine, she has been there for 50 years from Croatia. She can't speak English yet, which is a great pity. I mean, they should be given a chance to learn the language. It's very difficult for the Education Department to do this, there should be some other kind of possibility from the community to give them a chance.

With translators or interpreters, the frequency they're required and the difference between translators and interpreters, because many people think interpreters and translators are the same thing. Dietary needs, cross-cultural training is an integral part of planning.

MS SCOTT: If you could make your last point now, because we have to move on.

MR GEBELS (NEDA):   Just what I said or - - -

MS SCOTT: No, could you draw a conclusion?

MR GEBELS (NEDA):   I'll do my best. Other topics handled by NEDA are in collaboration with different people of different organisations, including Sydney University and other universities and peak organisations and regular communications with other leading Australian organisations. NEDA supports key points with the Commonwealth General's Department who is in the process of developing the Australian government's national report on human rights. The NEDA submission highlighted areas of discrimination and its consequences for people from non-English speaking background with disability, their families and carers. NEDA pointed out that an anti-discrimination law is not effectively dealing with the situation momentarily.

MS SCOTT: Thank you very much. Thank you for you testimony this afternoon.

MS SCOTT: We have three speakers who have got five minutes each, if you'd like to come forward and make impromptu comments. I think the first of these is Mary Walsh.

MS WALSH: I am speaking tomorrow and I know there won't be a capacity for generalised comments tomorrow so I just wanted to add a couple of things in relation to some of the - - -

MS SCOTT: Your name, just for the record.

MS WALSH: Mary Walsh.

MS SCOTT: You're representing yourself?

MS WALSH: I'm a community advocate in the Wide Bay Burnett region.

MS SCOTT: Thank you.

MS WALSH: My submission you have already received. In relation to some of the comments today, I have been involved in setting up a one-stop shop and 1300 numbers don't work, they're too impersonal. But I have got a detail of how it was all done and I'm happy to give that to you. I guess one of the other comments is in relation to the Queensland legislation under the Disability Services Act, as someone mentioned, no one single service provider can provide all services, especially not on one site and this is why you have such crisis, particularly in this state. Management at the moment is by crisis and has been that way for the last 30 years.

There is a difference between housing and supported accommodation and I was interested to hear some of the comments about flexibility versus accountability. It is a tricky subject. I'm an accountant by profession. But the other one that was mentioned was the necessity for support workers, and they're very different to carers - and I've gone into that in more depth in my submission - as opposed to people who are trained and who have qualifications. I think there is risk if you actually carry that too far because, if I could give you an example - and I actually do support cluster living, depending on the size - but I would think that perhaps a community lounge, kitchen. My son actually lived in a group residential, not permanently, he was there through the week and he would come home on weekends or when he was sick and he was sick a lot. So he had the best of both worlds, the same as my other children. My other children got married, got their own homes, went and formed their own lives. My disabled son did exactly the same in a different way.

The issue where you have people living in a group situation - and I guess some of the examples that were listed today - is you must have someone qualified on site if those people need supervision. It's not good enough to say, "They don't need to be qualified, as long as they've got the same vision and the same morals." It doesn't work that way. Litigation today is very, very much different to what it was years ago. My son actually did die in one of the residentials. He was on his way to work and he walked out of the bathroom and had a massive heart attack. The issue was that he had to have an autopsy. I mean, it was a very well-trained - it was an excellent example of supported accommodation. But the issue is if you have someone there who is not trained and who is not qualified and they are not observing all the workplace health and safety requirements, then you've really got a very big problem because it's litigation and if you have to sue - if someone goes to that degree, then there are problems.

There are some people who might never ever be able to live in individualised circumstances. I know the word "services" is an anathema to some people but there are a group of people in our nation who actually will always need that. The other thing is that with housing, individual housing, individual funding and block funding, we need to be very careful when we're looking at the modelling, I'm sure you're very well aware of this. In going down the totally individualised funding options you may rob service providers of the capacity to adequately financially survive and I've done the numbers on all that from a financial perspective. So the issue with that is we do need to be very careful, perhaps it should be a combination of both. I think Queensland's going down the path now where they might be going too far one way. But could I say that they went too far the other way 15 years ago.

They're just the generalised comments with one exception and that is, in marketing and promoting disability, we concentrate on ability, as we should; however, the people who need the most - and I always say "the too-hard basket", which is terrible, but I've been involved for 40 years at national, state, international and local level and the thing is the people who need it most are not the ones who in fact have the benefits for media or marketing promotion purposes so therefore they do get pushed to the side. I actually am involved with a family who live two hours out of the nearest capital city. The dad is 81, the mum is 78, they have three adult children, 50, 52, 54 and two of them still live at home, one has been placed in care and those parents have never, ever been on a holiday. They have never been away from their property in all that time. If they go, the whole family has to go. If they come into town for any reason whatsoever and I meet with them, I meet with them in the car or at a table or Coffee Club or somewhere where there's sufficient support with us, all to support the other family.

So that's how they manage in regional Queensland, the same as they manage in all the other regions of Australia - with a lot of difficulty. I would like to think that policy-makers would know a little bit about it but, unfortunately, they often don't.

MS SCOTT: Thank you very much.

MS SCOTT: Belinda. Just state your name and if you're representing yourself and off you go.

MS McAULIFFE (PTPA): Okay. I'm Belinda McAuliffe, I am representing myself. I have two children with disability. I'm also representing the organisation I work for, which is Parent To Parent Association Queensland. Parent To Parent is funded by Disability Services and has been for about 10 years now. Catherine and Jeremy, who spoke this morning from Pave the Way, do a similar project with succession planning as we do. My role is family facilitator and I've been doing that for four years now in a paid role and before that volunteered six years part-time. I'm a single parent and I have been for eight years. It's been a challenge to care for my daughter, as well as to do my work, to do study, training and assessment and things like that.

In part of my role with Parent To Parent, who is affiliated with National Council on Intellectual Disability, has been as a reference group member with Centrelink and so I used to go to Canberra twice a year for the past four years. Some of those comments this morning about forms and so forth is actually one of the things that we looked at while we were on the reference group and continue to do so. That covered all kinds of disabilities. I would just like people to know that actually those kind of reference groups are out there and there's a lot of input and that's always ongoing.

With the planning side of Parent To Parent, the succession planning, pretty much what we do is in congruence with what Mamre does. We look at future planning, we base it on gifts, strengths and capacities, and at the moment I've been working quite heavily in the community living initiative helping people to write support plans for those applications. Prior to that I have helped to develop some services. One was with ageing carers on the Sunshine Coast. The other is in Gympie where I live. I guess part of that role is looking at parents as carers in that role and sharing those experiences with other families and so I guess I've had the benefit of working with older carers whose children are now wanting to leave home. My daughter is only 15 so that's a long way in the future for me. I can see the struggles that people are having now by doing it all themselves and not looking at alternatives.

One of the other points I wanted to mention was for myself and a couple of other parents I know who have done the mortgage thing, own their own homes is one of the people I know has actually contacted Treasury or housing or something about the tax breaks, you know, having the benefits of - you're unable to work full-time, you've gone through the marriage break-up and everything else, so if there were other incentives that people could own their own homes, which then provides security for their child in the future, obviously that's going to take a load off the government in the future and also off siblings, because I have three other children.

The other thing I wanted to talk about was the issue of entitlement. Parent To Parent's work is based on a lot of person-centred planning, the work of Helen Sanderson Associates, John O'Brien, people in the United Kingdom and the United States, the entitlement process where people have an amount of money, dependent on what their disability is, what their needs are, regardless of where they live, whether they were born with it or whether it was an injury they acquired later. My daughter was diagnosed with a rare syndrome at 10 days' age. She acquired 10 specialists bang on the dot. That's as life changing as someone who has had an injury and had that change in their lives, yet I think quite often you don't have that road to help you find what you need to find and quite often parents are struggling to do that, and if they're tired, if they miss an appointment, if they don't do something that's suggested quite often you drop off the map and that help and assistance you're getting stops. We missed an ophthalmologist appointed, we've now been stuck on the bottom of the list, we have to start again yet she's been seeing him for 14 years. These are the kind of stupid things that you've got to go through. I guess if this kind of a scheme was set up that was national and everything was treated the same way, it would be a lot easier.

MS SCOTT: Do you support the idea of a national disability insurance scheme?

MS McAULIFFE (PTPA): Yes, I do. I guess there have been a lot of comments today, the pros and cons of that and obviously it's got to be paid for in some way and if that comes out of - if everyone pays a percentage of their tax like a Medicare levy - I do that myself, I pay my taxes. If it comes back to help me - if I get hit by a bus tomorrow, so be it.

MS SCOTT: Thank you very much.

MS McAULIFFE: Thank you.

MS SCOTT: Okay, Henk.

MR HORCHNER: Thank you for allowing me to speak for the second time and I thought I'd use the opportunity to answer some questions. John asked a question earlier about volunteering and network, networking and how to get to volunteers around you and it reminded me of the Canadian Vancouver model where they got about 20 or 30 people in Vancouver where they built a network around each particular client. We have the same - what we make a reference to today is a cluster. In Brisbane we've got different organisations who have got about 10 clients. But I'd like to warn we are the moment looking at 700,000 people nationally, although I commend all the small organisations in Australia, what they're doing and the effort to everybody. We're talking about something that's massive.

How can we possibly apply every little model that looks after one, two, 10, 20, 30? I represent an organisation that's got over three and a half thousand people and we've got 750 parents. Of the 750 more than 50 per cent are old. David talked about surveys. Have you ever tried to do a survey of elderly people where they're parents of disabled people? When you ask them they say, "Oh, no, it will be all right. It'll be okay," and everybody's quite happy. Then you go down and say, "Well, let's take a list? What do you do here and what do you do there?" and you have a list of about 20 or 30 questions and all of a sudden you find how many holes are in the support, that they're not right at all.

I want to say a word of warning, be flexible in your surveys. Do not take them at face value. At the moment parents when they get a survey they say, "What, another survey. What will the outcome be?" Because they've been asked so here in Queensland for a survey and they never have an outcome. I supplied you with some figures there on CSTDA. They are of the first, second and third national agreement called the Commonwealth, State Territory Disability Agreement.

MR KALISCH: We've got the numbers.

MS SCOTT: We've got the numbers so don't worry about that. We're looking into those.

MR HORCHNER: Yes, but you've got more than that. I worked out the percentages. I also worked out the percentages per capita. Look at them closely and you'll be amazed - because they didn't sign number 4 - as to what the states were given. So I say look outside the square. One gentleman mentioned Centrelink. I was asked that my daughter, who was in residential care at Warwick, come to Brisbane because they want to talk to her. I said, "Okay, I've got no problem to go and get her." "It'll cost me $50 there, $50 back for petrol, are you going to refund me?" "No." I said, "Okay, I'll go and get her," I said, "but once I bring her to Brisbane, what do you want to do with her?" She said, "Talk with her." I said, "You've got the file in front of you?" She said, "Yes." I said, "She hasn't spoken a word since she's been born." So I say look outside the square.

We're talking about individual cases. I can tell you, Mr Hamilton, I take my hat off to you. I'm sitting here with a very multiple fractured back. I broke my spine by falling through a roof as a state emergency volunteer. I sued the state government, it cost me $84,000 in legal fees because I couldn't sue the state government, I had to sue the owner of the shop. He turned out to be a Supreme Court judge. I did not win my case, which would have entitled me to about two or three million dollars worth of damages. I still haven't paid my $84,000 fees to Suncorp. I must admit it cost me $68,000 in legal fees and the state government have given me since, 15 years later, an ex gratia payment. I'm still on painkillers. I admire your spirit. I can at least walk and I know what you're missing.

I can give a lot of personal examples. I worked as an apprentice electrician in the 50s at Goodna Mental Hospital. We used to arrive there by train and we walked through the golf course and we walked what we used to call the cattle pits and by the time we got there 7.00 or half past 7 the patients had been let out into these cattle yards, which were facing up from the road with a shelter shed on the top, and there was no grass in it and the women used to race down to the bottom as we walked past as young fellows and I can tell you that many things happened while we walked past. I worked in the nurses' quarters in Goodna Mental Hospital where the nurses had been attacked and were on day or night shift.

MS SCOTT: Henk, your last point.

MR HORCHNER: So all I say to you, look for the need. Do not get confused by small individual examples. You are dealing with 700,000 clients. Start now to find out exactly where the problems are, set a definite date line and accept that date line regardless - think out of the square. If they want your report by February, set a date line now as an interim and say, "As from 1 January we recommend to the government," or whoever they are, "to start doing the survey as to what the conditions of people's disabilities are," and my offer still stands. I'm available every day of the week for you, if you want me.

MS SCOTT: Thank you.

MS VETTER: Sorry, I missed my name off the list.

MS SCOTT: Do you actually want to say two things?

MS VETTER: No, a bit more than two.

MS SCOTT: Would you like to come forward. If you can give your name for the record.

MS VETTER: My name is Anne Vetter. I'm the mum of three kids. Our firstborn is 19, our second is 17 tomorrow and our third is 14. Our second child who is 17 tomorrow, his autism didn't become apparent until he was three years of age and at that time we had a baby who had reflux and a demanding preschooler. So life was pretty busy and we had only just moved to our new town of Gympie, we didn't have any close friends, we had only been there four months and my family lived in Toowoomba, my husband is in Charleville, so were pretty much up shit creek. But anyway, we bumbled along.

Going to your issues paper, page 3, the first dot point, "Provides long-term essential care and support." Could I just suggest pay support workers more than cleaners and the shelf fillers at the supermarkets for a start, look after support workers. If they're only getting a few hours here and there, naturally they'll need to move onto an employment sector where their income is more reliance. Look after the unpaid carers, do a profile on unpaid carers. How many die prematurely? How many die not long after the person they're caring for passes away? That happened in the case of my sister whose daughter was spina bifida and when my niece died eight years ago, my sister died two years later. How many smoke or drink or take drugs or are overweight? Gym fees could be reimbursed to encourage a healthy lifestyle. Why not when smokers, who aren't necessarily carers, get their quit smoking program subsidised and drug addicts receive free methadone programs and alcoholics receive treatment as well as participation in AA groups, why can't there be some sort of preventative maintenance assistance for carers?

Unpaid carers should be treated not in crisis mode, but in preventative ways, eg, regular massage, physiotherapy treatment. Often carers have back issues because of the nature of the work and this goes far beyond looking after the person who is physically disabled but includes dealing with people who have oppositional behaviours and, for their own safety, often need to be physically reigned in, like my son who has autism, or whose condition is such that the only way they can focus and learn is by encouragement and facilitation by another person. Carers of people with physical disabilities often would need psychiatric assistance as well because it's usually backbreaking work and the person with the disability can be, with all due respect, very demanding. Subsidised accommodation for decent respite breaks. The Commonwealth carers offers breaks but only when the carer has got to crisis point and there is that word again, "crisis".

The second dot point on that page, "Manages the cost of long-term care." Is it true that aids such as communication devices for the non-verbal, such as my son, and wheelchairs for the physically disabled and other devices to assimilate people into an inclusive, welcoming society are free in New South Wales? How can we have reliable long-term care for our disadvantaged in the community when often support workers provide casual work only - that's a bit of repetition - and therefore we lose well-qualified support workers who choose job and economic security often that comes with permanent hours.

The care industry needs to be seen as a valid career option and not something to do to earn some cash to supplement their own pensions which is often the case; they're quite often in receipt of pensions themselves. We've had support carers who, every time they bring my child back, they tell us about their problems, which has been the bulk of our experience. We've had some wonderful carers. If the caring industry was elevated to career status and included in high school employment expos, for example, it might open people's minds to a career that they hadn't otherwise considered.

Point 3 on that page: guarantee that the disadvantage won't be worse off under your insurance scheme proposal. Point 5: accommodation. It's everyone's dream to live in attractive accommodation. So could we include the word "attractive" in assimilated residential housing; not so much in clusters. Aids and appliances: I know of a woman here in Queensland I was only talking to her last week. She paid $7000 for her own wheelchair. It had to have proper neck support and the whole works. Our son has autism and he's non-verbal. If we were to purchase a communication device we'd be looking at around the $5000 mark - for a device that he could throw over a fence and wreck because he just throws things over our fence and the same at school, everything has got to be thrown. I was told but not sure how true that such aids are free in New South Wales.

Accommodation, aids and appliances, et cetera, but no mention of the word "therapies". We've spent a lot of money over the past 14 years with speech therapists, et cetera, and don't get too much back from our private health insurance. Unfortunately the recently introduced rebated costs for people with autism was introduced too late for our family as our son is too old at 17 to qualify. Point 7: I'd like to see this include encouragement and assistance to establish low cost private enterprises. In your part there about employment, education and training, why not also someone owning their own business because a lot of these guys are going to have to have their support workers so they'll work quite functionally. One would hope that the two together would work as well as one would.

So education, training and employment are included but will either of these three include people who need the one-to-one support. My son has autism and intellectual impairment and there's very little that he can do without support. However, great things are possible with support. In other words, will there be, for example, education, training and employment programs of varying degrees, not just "where applicable" as I think the wording says. (Modifications to make sure that the person with an intellectual disability or severe multiple disabilities are not ignored.)

Regarding education: does this refer to inclusive education and will it be from preschool to high school completion, and uni if viable? If it does include mainstream education, then it won't work if parents have an option of mainstream or special education units because society places a lot of pressure on parents to complacently place their children who need extra attention in with a load of other kids with varying challenges. Also, adults with challenges often tell of personal unsuccessful, heart-wrenching stories of their so-called inclusive mainstream education in which they were usually ostracised and, worse still, ridiculed as if they were deaf. However, if inclusion is the norm, then surely this would minimise such negative, unhelpful attitudes, often by parents of the normal kids as well.

We dabbled in the mainstream education when our son was only seven. All the Queensland government could offer was five hours per week of the one-to-one support he required to, at best, remain in the classroom and, more so, actually on the school premises. Other parents of students at the school who had mild learning disorders were resentful of the hours that were directed to him. Special schools should be, therefore, dismantled, or the concept of, and the talent of qualified teachers from within those schools should be utilised and embraced because there are some wonderful teachers and teacher aides amongst them. Like all careers, though, our personal experience with the teachers at our son's special school is that there are good and bad amongst them, and before offering them automatic placement within a mainstream school, their individual records should be scrutinised to determine their real values about students with disabilities.

Page 4 of your issues paper, part 2: how can you contribute to this inquiry - the first paragraph. Another reason for the frustration is the lack of long-term commitment by the government to an individual. For example, we don't receive any recurrent funding. Our son graduates from special school at the end of next year. I have a number of small enterprise ideas for him. However, because I have no idea as to whether he will receive funding for the start-up costs and the ongoing one-to-one support that will be needed to help him engage in the enterprise, I can't take my plans very far. This is very unsatisfactory. The Queensland government is spending lots of resources on inclusive workshops, yet most of these workshops seem to focus on whether Freddy gets linked up with a fishing club on the weekend. Wouldn't it be great if Freddy actually had a Monday to Friday life, just like the rest of us.

MS SCOTT: Anne, given you've got text in front of you, I'd be happy to take it and for it to become a formal submission.

MS VETTER: Yes.

MS SCOTT: If we have you read through all of it, that would mean that we would take quite a bit of time. Would you be able to just say one or two sentences - any other views you have in addition to that submission. We'd be happy to take - we've got a certain contract here, we've got to be out soon.

MS VETTER: Yes. So finish talking now?

MS SCOTT: If you could. Anything else you would like to say?

MS VETTER: No. Just that I found out about this NDIS by accident only about three or four weeks ago. I spoke to a woman this week who has severe disabilities and she's non-verbal, but she's very articulate when she types and she's very intelligent. I asked her was she coming today and she said, "I don't even know what the NDIS is." This is a woman who had shared housing arrangement. The person died, I think, and she got pushed into a nursing home in New South Wales. Some friends advocated strongly on her behalf. They got her out of the nursing home; she's now living here in Queensland with her daughter and son-in-law. Her daughter now has severe disabilities, I don't know of what sort. Her grandson that she's living with has mild autism. She doesn't have a carer, she doesn't have any support, and she's happy; that's her choice. I mean, that's a woman who could offer so much. She didn't even know about it. So I have some concerns as to how far-reaching - how you've promoted the Commission. I want to thank you so much for setting up this Commission. Thank you.

MS SCOTT: I now draw this hearing to a close and we commence tomorrow at 9 o'clock. Thank you.

AT 5.37 PM THE INQUIRY WAS ADJOURNED UNTIL
FRIDAY, 16 JULY 2010