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# TRANSCRIPT OF PROCEEDINGS

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**PRODUCTIVITY COMMISSION**

# INQUIRY INTO DISABILITY CARE AND SUPPORT

**MS P. SCOTT, Presiding Commissioner**
**MR D. KALISCH, Commissioner**

**TRANSCRIPT OF PROCEEDINGS**

**AT SYDNEY ON WEDNESDAY, 21 JULY 2010, AT 9.10 AM**

**Continued from 20/7/10**

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**MS SCOTT:** Good morning and welcome to 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 for this inquiry. My fellow commissioners are David Kalisch, who is here with me today, and John Walsh, who is unable to be here today but will be, of course, reading the transcript. He has been here the last two days but couldn't make it today.

The inquiry started in April with a reference from the Treasurer. The Australian government has asked the Productivity Commission to examine the feasibility, costs and the design and benefits of a national disability scheme that would provide long-term essential care and support; manage the cost of long-term care; replace the existing funding for those presently covered by other schemes; 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 aides and appliances; respite; transport; day programs and community participation; assist people with disabilities to make decisions about their support; provide for people to participate in education, training and employment where possible.

The Australian government has asked the commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes considerations of a variety of options, including a no-fault social insurance model and approaches used in other countries. We've already talked to a range of organisations and individuals with an interest in the issues. This is our last day of hearings here in Sydney and we're on to Perth and then we'll finish our public hearing process for this stage of the report. We issued 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. The commission has extended the due date for initial submissions to Monday, 16 August 2010. The commission welcomes second or even further submissions after the due date of initial submissions. These submissions may include additional points you may wish to make, comments on other people's submissions, comments on what you hear today and the results of any community consultations you're undertaking. The purpose of these hearings is to provide an opportunity for interested parties to discuss the submissions and their views on the public record. We will be releasing a draft report in February next year for public comment and to invite participation in another round of hearings. It's very important that people stay engaged to see the February report because it will include draft recommendations and a draft design of a proposal.

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 if you wish to make comment on anything you hear today, please feel free to do so by making a short submission to the inquiry. 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. Transcript will be made available from the commission's web site following the hearing. I now welcome to the table Leah Hobson. Good morning, Leah.

**MS HOBSON (AFDO):** Good morning, Patricia.

**MS SCOTT:** Leah, could you indicate for the record the organisation you're representing and would you like to make an opening statement. You have about 25 minutes for your presentation and for our discussions.

**MS HOBSON (AFDO):** Sure, I'd like to make a very brief opening statement and just to confirm for the record I'm Leah Hobson and I am from the Australian Federation of Disability Organisations. I'd like to begin by just thanking the Productivity Commission for allowing us the time to speak to you this morning and by acknowledging that what the Productivity Commission is looking at doing could bring about some very fundamental change for people with disability in Australia. The way we see that fundamental change would be ensuring that the human rights of people with disability are met in a compelling and an empowering way under the United Nations Convention on the Rights of Persons with Disabilities.

When the UN convention talks about disability it does so with a broad definition. It talks a little bit about categories of disability but it doesn't list different disability types which are to be included and it certainly doesn't prioritise which disability types need more assistance than others. It also is very inclusive in terms of recognising the flexibility that people with disability require in order to have their needs met. For example, under the definition of communication in the UN convention, it talks about a range of methods of communication, so that's verbal, written, braille, audio, sign languages, augmentative and assistive communication devices, so recognising that not only is there no way to prioritise people with disability in terms of disability type and disability severity when we're talking about basic human rights but there also needs to be a range of flexibility there for people with disability to fully participate in society.

The convention also doesn't, quite deliberately, prioritise which areas of participation should be met first. It talks about the fullest possible civic, political, economic, social and cultural participation of people with disability in society and in part it does that because for people with disability the rights that the rest of the community might consider as just given are not necessarily so. So when we think about freedom of speech, we're talking about communication as an example, most people in Australian society would say that they have freedom of speech unless the government decides to go in for a spot of censorship. But for people with disability, if you don't have access to the communication methods that I outlined before or if you have a imbalance of power in your life, if you have perhaps support workers who have control over your finances or you are in a service situation where the people who place you in a group home also place you in a job, you're not necessarily in a position to exercise your freedom of speech.

So when it comes to developing a lifetime care and support scheme AFDO believes that at a fundamental level eligibility should be for all people with disability who need support, regardless of how they might identify or define their disability and regardless of how they might identify or define support. It should allow those people with disability to have the greatest amount of decision-making and choice within the process of accessing the supports that they need to participate in society. AFDO believes that a key way of doing that is through something like a disability inclusion allowance which would be paid directly to people with disability who would then be able to make some decisions, either with support or without it if they feel capable of doing so to get the supports that they need in their life.

Such an allowance would need to be nationally consistent, it would be nationally portable, it would need to be flexible in terms of meeting that broad range of needs that I mentioned earlier and not to mention the broad range of life circumstances that all of us find ourselves in. In addition to that AFDO believes very strongly that any system needs to have other structures in place, it needs to be providing people with the sort of information and advocacy support that they might need to make decisions clearly. It needs to be providing for workforce development so that the services and supports that people need are available when they need them. It needs to be also providing people with disability a clear understanding that the community is engaged in their participation as well which is why we believe that the system should be funded through a specific tax on the general population.

We're also mindful that when we're talking about community engagement one of the issues here has to be acknowledging that when we pass over responsibility to the individual, there may be a perception in society that then institutions, organisations don't have to front up for the cost of access when our laws clearly state that they do. So, for instance, if an individual is getting some funding for interpreters and then they want to go and study at an educational institution, it is still that institution's legal obligation to provide an accessible environment for a person with disability.

Perhaps the most critical thing we believe is that people with disability should be at the centre of planning a lifetime disability care and support scheme. They should be at the centre of governing it. There shouldn't be about us without us. Thank you.

**MS SCOTT:** Thank you.

**MR KALISCH:** Leah, you talked about the UN convention and in our issues paper we refer to it as well in terms of the way it sets out different obligations on Australia and a number of other people have mentioned it to us over the course of the hearings in different locations. I suppose one of the challenges is actually to operationalise such a convention. You've started to give us a number of those key elements about how you could operationalise it. Do you envisage that the scheme that you talked about in terms of eligibility for all who need support, decision-making and choice for people with disabilities, direct payments to people with disability and then the nationally consistent, portable and somewhat flexible payment arrangement, do you see that as meeting the requirements of that convention?

**MS HOBSON (AFDO):** Look, I think meeting the requirements of the convention is one of those things that, regardless of what we do in society, is always going to be an ongoing exercise. We're talking about people's attitudes to disability, we're talking about an environment where what is constituted as disability can shift over time. But certainly a scheme like this would go a significant way to addressing the rights of people with disability. I would emphasise too that the extent to which it does that is very much related to the way in which it is implemented, how carefully it's implemented, how much participation people with disability have in that process.

**MR KALISCH:** One of the things that has struck us a little bit from some of the people that have been presenting to the inquiry and some of the submissions we have received has been the different level of support required by people who seem to have similar needs and that is because they have either informal supports and family carers and others that help them or because they are more able to utilise money in an efficient manner, but there seems to be quite a difference in terms of what people actually require in terms of funding. Is that something you're also aware of?

**MS HOBSON (AFDO):** Certainly. You've identified some of the reasons there why that would be the case that some people have better access to informal supports. Another important aspect is that some people with disability have access to better information about what's available to them. Often people with disability kind of stumble across information about a service or a support. I was doing a consultation down in Wollongong yesterday and a person with disability who had been homeless at the age of 16 talked about going to Centrelink and saying, "I have a disability and I need some supports," and Centrelink saying to her, "There's no supports available to you here." It was only through her then having a conversation with someone else, a friend, who said, "Why don't you go and talk to the Salvos," and the Salvos had some contact within the local disability service system and were able to connect her properly.

So it's about those connections, about knowing what technology and what services and supports are actually available. It's also about how effectively you can navigate the systems around you and that's both the disability-specific ones and the mainstream systems as well.  It might be that the first time you go and speak to someone at your local council about getting home and community care they say, "We simply don't have the services available to fund you, but we recognise that you have the right amount of need."  If you're articulate and capable and you haven't been living a life where - you've been taught to comply and be grateful for what you've been given, which is the experience of a lot of people with disability, then you will be able to kind of push them a little bit and maybe get yourself pushed up the list and get the supports that you need.  But if you have not been that kind of access, if you don't know about advocacy that can support you, then you're left out.

**MR KALISCH:**   Just one further question from me for the moment.  Do you envisage that any formal scheme which provides funding should make allowance for those that do have informal supports?

**MS HOBSON (AFDO):**   I do.  I think that people with disability and their families and those around them can make decisions about what they want formal support to look like in their lives and that's one of the reasons why it's so important that assessment processes that look at the needs of people with disability are conducted under a self-assessment model, in part because experts who may specialise in looking at somebody's physical needs or their intellectual capacity or whatever else are not necessarily going to look at all of that in the context of their entire life and in the context of the decisions that they and their family and others around them might want to make.  But it should also be very clear that the system doesn't necessarily mean that you have to put up with just having informal supports if what you really want is a formal support in place of what you're currently getting informally.

**MR KALISCH:**   Thanks, Leah.

**MS SCOTT:**   Leah, it's good to see you again and I think this is about our third opportunity to have a chat, so that's good.

**MS HOBSON (AFDO):**   I think so.

**MS SCOTT:**   I just want you to clarify a few things.  Your organisation supports the idea of a national disability insurance scheme.

**MS HOBSON (AFDO):**   That's correct.

**MS SCOTT:**   And you want to have a disability inclusion allowance, that's in addition to the NDIS?

**MS HOBSON (AFDO):**   Well, for us the NDIS provides a structure for funding.  It then leaves us with the question of how that funding is used and for us one of the key aspects is a disability inclusion allowance, an allowance that goes directly to people with disability. But as I flagged in my opening statement, I think that there is also a range of other infrastructure issues which need to be addressed as part of a broader national disability insurance scheme.

**MS SCOTT:** Just have patience because I've got lots of ideas swirling around in my head, so I just want to systematically go through this and see how we go. One of the terms of reference is that we have regard to the concept of individualised care, that people would be assessed on their individual circumstances and receive support reflecting their needs. So it's very much individualised and, of course, one of the things that people have pointed to is pilot schemes or sometimes schemes that have operated in a number of states and the UK models of In Control and how it operates in some other countries where a person is assessed for their needs, they might be asked what their needs are, there might be some self-assessment part of the process and then funding could be paid directly into their account and then they disburse the money as they see fit, that they spend the money on therapies and they spend the money, if they wish, on things to keep them in the community.

If it turns out that they don't want to make those decisions or are not capable of making those decisions, that payment could be directed to either a broker or their family or someone who cares for them to disburse the money. So I'm taking it that those ideas are part of the NDIS. Are you comfortable with those sorts of broad concepts?

**MS HOBSON (AFDO):** I am comfortable with those sorts of broad concepts.

**MS SCOTT:** Okay. The disability inclusion allowance is in addition to that though, is it?

**MS HOBSON (AFDO):** No, the disability inclusion allowance is simply a way of describing that sort of a scheme, so it's a way of naming that.

**MS SCOTT:** Okay. So it's the individualised funding element of the scheme.

**MS HOBSON (AFDO):** Yes, that's correct.

**MS SCOTT:** So someone could be assessed as requiring 15,000, another person could be assessed as requiring 10,000 or 110,000, depending upon their level of need?

**MS HOBSON (AFDO):** That's correct.

**MS SCOTT:** Okay, got that. All right, that's a terminology issue. Do you envisage housing being in the scheme or supported accommodation?

**MS HOBSON (AFDO):** Well, when we're talking about housing, somebody's ability to live in a place of their choosing needs to be supported. So if somebody has some issues with perhaps doing some cleaning or whether they have issues with personal budgets and cooking, those sorts of things, then they should have the support to do those things and be able to live as independently as possible. We also think that obviously people with disability need access to accessible housing and that's an issue that needs to be considered. But when you're talking about housing as a service, people with disability should have the same ability as everybody else to live in the community to the best of their ability. I suppose one of the issues that we see as problematic is the current trend of group homes and medium scale and large scale institutions which still exist in Australia.

Of course some people with disability want to live in a group home environment and are quite happy to do that but there is a concern that that creates kind of ghettos and segregations for people with disability and we need to be very aware of avoiding that wherever possible. So when we're talking about supports to help people be in accommodation, yes, but there needs to be a broader conversation about what that looks like.

**MS SCOTT:** Would you like to talk about that because this is, I think, the time to have that broader conversation because our terms of reference refer to accommodation needs.

**MS HOBSON (AFDO):** For starters, as I was saying, we would very strongly advocate against a move which doesn't allow people to have choice of accommodation in the first instance. There are some places in Australia, like here in New South Wales, where institutions remain open and governments are working to further the existence of those institutions rather than seeking to close them down. So we still have something like 4000 people across Australia, according to the 2008 National Minimum Data Set, living in large scale or small scale institutions in Australia. Then we have boarding houses and hostels which may or may not be recognised as institutions but which are essentially a large number of people with disability living in the one premises. They may or may not be for profit and allowed to be for profit by government and those sorts of situations open people with disability not only to being segregated from the community, but to abuse and neglect by the people running those sorts of institutions.

I've heard the story of an advocacy agency going into a boarding house where they may have been 10 or 15 people with disability living there and finding that the staff there have had one doctor coming in to see everybody, doesn't really see the people, just writes out the scrips for the staff because he gets bulk billed for those 10 or 15 people all at once and can spend a minimum amount of time and then the staff are left to administer the medication which may not be appropriate, may be very high dose levels of medication.  The advocacy agency went in and found people who were catatonic and on four or five times the level of medication that they should have been on.  Those kinds of places are very much open to abuse.

Group homes - as I said, sometimes people with disability are quite happy to be in that environment but more often than not they're not an accommodation service of choice.  It's basically that people with perhaps a physical or intellectual disability or some other kind of disability require support to live away from their family and that is the option that is available to them.  I spoke to a service provider in a rural area who was saying that they just hold their breath and wait to see where a particular person will be placed.  It's not about whether that will be in the same town or the same local council area as their family, they might be 45 minutes, an hour away. They certainly don't get a choice of being placed with people who they like or who they get on with.  In some cases the accommodation is actually provided by a service provider who might also be providing other services in that person's life.

For instance, a person who is living in a group home might also be working in an Australian business enterprise, disability enterprise, that is run by the same service provider.  I'm sure you can imagine the kind of problems that would exist for you if the Productivity Commission paid for your rent and paid for your house and gave you a job as well, that if there was a problem at work or a problem at home, you wouldn't necessarily want to complain about it as much.  So it's that implicit kind of powerlessness for people with disability when that situation occurs.  Ideally people with disability need to be given the opportunity to be asked, "Where do you want to live?" and then to be facilitated to do that and in the community as much as possible.

I just also want to flag with housing that one of the problems that some people with disability have mentioned to us is that, of course, many people with disability - I think about 13 per cent of the public housing population is people with disability, that's a statistic from a Senate inquiry which I think I can track down for you.  For those people the system of public housing isn't particularly flexible.  Again, that's tended to be more about the supply of accessible housing but also then about if people with disability feel vulnerable in public housing estate because they're being harassed, then they're told, "Put up with it or move out.  Get yourself into private accommodation."  I heard of an instance yesterday where that has happened for somebody and that person has wound up living in a caravan park, that sometimes people with disability are labelled as living in squalor because of their disability and because they don't have the supports that they need.

So there are those sorts of issues in terms of mainstreaming people with disability and then when you get to the private housing market, there's issues for people with disability who again need accessible housing, but also for people with disability when you're looking at renting or buying a house and maybe you need to take into consideration living near a train station or living near a particular service or, in my case, a backyard because you've a guide dog, having some particular facility set up where you live. There are all those sorts of considerations to do with housing that are not necessarily about providing a service as well.

**MS SCOTT:** Give the poor status then of housing options and accommodation options and problems you've outlined, what recommendation would you have for the commission in terms of what we should find and what we should recommend to the government about housing and accommodation?

**MS HOBSON (AFDO):** As I said in there somewhere it has to be about providing people with choice as to where they live and the emphasis of support for housing and support for accommodation should be about offering that level of choice to people with disability rather than putting them into a clustered environment or putting them into an environment where they can only live with other people with disability without that choice. But also that there needs to be systemic advocacy work on some of those other issues that I talked about: the issue of closing institutions, the issue of making sure that public housing stock is accessible and looking at the issue of what happens when the cost of your housing goes up because you're in the private rental market and you have particular accessibility needs.

**MS SCOTT:** You would advocate the systemic advocacy rather than a conclusion about institutions or public housing?

**MS HOBSON (AFDO):** We would certainly advocate that there should be a conclusion that large institutions and small institutions should be closed. We would certainly advocate that perhaps a percentage of public housing stock should be made acceptable.

**MS SCOTT:** It's been put to us informally that because of the shortage of accommodation suitable for people with disabilities that in fact for some states effectively their public housing stock will increasingly become housing for people with a disability almost exclusively. What's your reaction to that given your concern about effectively cluster arrangements? Informally we could end up with a cluster arrangement that's called public housing.

**MS HOBSON (AFDO):** Yes, I would certainly share that concern that we could and that's too a broader issue about how public housing works in Australia. You know that public housing does tend to be clustered in estates but then we're already on a path towards the kind of semi-institutionalisation of people with disability. When we talk about people with disability, a large number are living on pensions, so they're either in public housing or they're clustered in the poorer suburbs across our cities and in regional locations because they tend to be older people as well. We're already seeing a kind of invisible segregation of people with disability in our community and I would be very concerned that that would continue.

**MS SCOTT:** Leah, thank you very much for attending today and for your evidence.

**MS HOBSON (AFDO):** Thank you.

**MS SCOTT:** Good morning to everyone, especially those that have recently joined us. We have changed the order of presentation and I'd now invite Sven Topp to come forward, please. Good morning, Sven, and for the record could you indicate what organisation you're representing, please.

**MR TOPP (ADBC):** I'm representing the Australian DeafBlind Council.

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

**MR TOPP (ADBC):** Yes, thank you. Basically I would like to just point out that in Australia the deafblind population currently stands at approximately 288,000 people, almost 94 per cent of that is over the age of 65 and that number is continuing to increase as the population ages. A recent study was done into mental health in that area and 95 per cent also suffer from depression and approximately 50 per cent of them also suffer from anxiety. There are mental and physical disorders that interact with deafblindness. A number of causes currently exist and there is a range of deafblindness present in Australia: there are those who are congenitally deafblind, there are those who are congenitally blind with later onset of deafness; those who are congenitally with later onset of blindness and those who acquire deafblindness later on in life, sometimes through accident or degeneration over time.

These four groups represent a very diverse group and each individual is, I guess, independent and individual on their own. So basically the consideration needs to be taken into each individual and they need to be assessed on an independent basis. Currently the main issue is social inclusion with many being in homes, both inappropriate and sometimes appropriate. Many of the younger generation are in homes for the elderly and that sort of care is not being provided appropriately with staff not being trained. There are other issues in employment with people requiring interpreters or appropriate work adjustments.

Housing too is also an issue. Many are not able to access the general market with some living at home with family needing respite or, as I mentioned before, in homes as well. I guess that will conclude my basic opening statement. I believe our submission can cover most of the things in depth.

**MS SCOTT:** Thank you.

**MR KALISCH:** Sven, thank you for the information you provided to us around the extent and causes of deafblindness, it was very helpful. I suppose it does raise one issue for us about particularly the provision of services and application to people of an older age, in particular the terms of reference that we received require us or ask us to consider a disability insurance scheme that does not take into account some of the natural ageing and the question of applicability of services for people of an older age. Are you expecting that deafblindness will primarily be a condition experienced by older people in the future?

**MR TOPP (ADBC):** That is a difficult question to answer. I believe that as our population tends to age and the longevity of age is increased over time due to science and medicine that I believe that will be an increasing number. But there are certainly possibilities that medicine may also be able to solve many of those problems too. But I believe we can't rely heavily on that, so I believe the ageing population is partly our responsibility and ensure they are appropriately taken care is a priority.

**MR KALISCH:** I suppose one of the issues that we're also considering in the Productivity Commission at the moment is aged care and services for older people in a companion research study being done by a number of our colleagues. Is that an area of concern or are there some good models of care in the aged care sector where people with deafblindness are being well cared for or is that an issue that we should investigate further?

**MR TOPP (ADBC):** The Australian DeafBlind Council has had some difficulty locating people who are deafblind in the aged group. This is generally because they don't associate with the deafblind - I mean, they don't fall under that category but many are isolated and unless they actually have support from family members (indistinct) so I believe that is an area of very big concern but it does require a bit more research and being actually able to locate the individuals who fall into that category.

**MR KALISCH:** So if I can just understand what you've said a little bit more and just check that with you, there is a concern that people are located in the community but you're not aware of them, and there might be a concern that the support that they're receiving is not fully appropriate for their needs.

**MR TOPP (ADBC):** Yes, that's pretty much it. I can give an example of my own experience. I had a grandfather who went deaf before I did, but he wouldn't wear his hearing aids or anything like that, so a lot of that age group are rather shy of having a disability because they grew up at a time when it was - what's the word - condemned or made fun of. Disabilities have come a long way since then but the older population was exposed to a lot of humiliation in that area. So many seek isolation and deafblindness is a very isolating disability too, very isolated, and we are not able to actually get in touch with them.

**MR KALISCH:** Thank you. I've just got one more question. You talked in the written notes that we received from the council about the costs of supported accommodation could be quite significant, in between 60 to a hundred thousand dollars per person per annum. I'm just wondering whether you could describe for us briefly the nature of the services that are required by people in those circumstances.

**MR TOPP (ADBC):** It's high variability. I believe if we could go to the previous presentation and write out what they said about providing individual care and accommodation but make an adjustment for the type of people where some care may be required in the home which can go from very personal care to simply going shopping or access to the community, so the actual provision of housing is an issue and the provision of living independently can be considered.

**MS SCOTT:** Sven, thank you for your testimony so far and for the notes that were provided today. I would like to ask you about what looks like an odd situation where funding for hearing services stops when you're 21. Have I got that right? What's the explanation for that?

**MR TOPP (ADBC):** That's a good question. I'm not that personally familiar with that area. However, I do know that a lot of funding goes to both the deaf and the blind services specifically, but the deafblind community tends to fall in the middle and is not actually receiving that much assistance from either of those organisations, especially due to the fact that most of them don't have appropriately trained staff. So at the moment there is a misconception that the deafness and the blindness organisations are providing high degrees of support to people who are deafblind.

**MS SCOTT:** Thank you. In relation to a national insurance scheme, what would be the benefits that you would see coming from a scheme that gave assistance to the individual rather than assistance to organisations through block funding?

**MR TOPP (ADBC):** Like, providing assistance to the actual individual, they would be able to identify the areas in which that funding could be spent and that would be appropriate for them, especially since there is such high variability between each individual in the deafblind community. But that does have a catch-22, in that some people who are deafblind may not have the time or the capability to appropriately manage their funds, so someone else may be able to provide those things.

**MS SCOTT:** Thank you. Would you like to talk about employment opportunities for people who are deafblind in Australia at the moment?

**MR TOPP (ADBC):** Okay. I'm currently studying at the University of New South Wales myself and I'm looking at a computer science degree. Presently there isn't actually much available going into the community and trying to acquire an appropriate job. I've looked at places like IBM and the big ones have good backgrounds and disability support. Many of them are able to provide their own individual support and actually provision from the government. However, outside of those, there is almost nothing at the moment and it's a very limited area of work opportunity. So if we're actually acquiring - a bit of support would be needed, even the inclusion of ongoing support for some, so that is something that needs to be considered.

At the moment there is some training I believe for people in the workforce for people with disabilities. While I'm not quite sure if that would be appropriate or not, there may be other areas - computers to be modified, large-screen monitors and bio displays, so there's a lot of technical support that is required. That also puts pressure on people are deafblind and people with disabilities in general to try and retain the job they are currently into because the opportunities outside their current position are slim. So once provision has been made, they would probably feel pressured to be in that position as much as possible, even if there is abuse or harassment in that position.

**MS SCOTT:** Thank you.

**MR KALISCH:** Sven, are you hopeful there will be employment for you once you've finished your degree?

**MR TOPP (ADBC):** I would like to say yes, but it's a good question. At the moment, I'm trying to get opportunities such as internships and trying to make inroads in that department. A lot of people with deafblindness don't have access to information, so basically they wouldn't know about that (indistinct) trying to provide that information too for people who have access to the Internet. But that's only getting in touch with a very small proportion of the deafblind population, so it's hard to get in touch with all of them at once to make sure they are given the information. The other thing I can think of is voting at the moment; we all have the right to vote but I have withdrawn my name from the voting roll because I can't get access to the appropriate information to make the decision I need to make and to make an informed decision.

**MR KALISCH:** That's unfortunate. Can you also talk about your experience with education, particularly going through school and now at university, how you've accessed information and been able to learn?

**MR TOPP (ADBC):** The university has been very supportive actually. I generally attend lectures, tutorials and laboratory sessions with the assistance of one of the interpreters. Generally that works out okay but there are certain adjustments that are required. For instance, trying to read the board can be difficult for me, it's actually impossible, but we tend to find that we struggle to keep up, whether it's the visual end or the auditory information, as compared to someone who is simply deaf, who've been given the auditory information but they can take in the visual information. But someone who is deafblind would require both the visual and auditory information at the same time, so it can be both confusing and difficult to keep up with. There is often a lot of extra reading that is required because you have to read the transcript from the lecture later and then take notes. You need to read the original material too and you need access to all of that information in large print or some people require that to be interpreted.

But interpreter availability is very short; I use a very specialised form of communication and there aren't that many people who are capable of doing it to a particular level, so that can be an issue. There are about six people who can actually do it and they are also employed for Auslan work. We try to find interpreters that are available on a regular basis during the week for lectures and tutorials and it can be very difficult. This current semester I was doing two courses but have had to drop back to one because there aren't enough people available.

**MS SCOTT:** Sven, could you talk about the value of early intervention versus waiting till a crisis occurs.

**MR TOPP (ADBC):** Well, I believe that's a bit of a no-brainer actually. It's important to have early intervention. That's basically because in terms of deafblindness, as I said, it's a very isolating disability. If you don't manage to provide early intervention many of them won't learn, practically (indistinct) those who are content to be deafblind, therefore left at home sitting in a corner in complete darkness and silence. Trying to install a formal communication method is very difficult. There are wonderful stories such as Helen Keller and other big names, but they are just as much a representation of the deafblind community as the amount of support that is actually required to provide that. Maybe the Miracle Worker probably represents a good idea of that, trying to support that it is needed and it is ongoing as well. It is not just a matter of early intervention but also continued support. At present there is a big concern in the deafblind community that by the age of 18 or so there becomes no support whatsoever and it suddenly cuts off and there is nowhere really to go.

**MS SCOTT:** So to clarify, early intervention is highly desirable but support cuts off at 18. What support disappears at that age, education support, assistance with - I thought hearing aid assistance disappeared at 21. I just wanted to clarify what assistance drops away at 18.

**MR TOPP (ADBC):** There are a number or organisations that provide support after that. I think it's not so much the organisations but that family support becomes more strained after that point in time. There is no support from schools or early intervention people or people who deal with specific disability centres (indistinct) assistance drops off at 21. There are no other support agencies. In the eastern states there is Vision Australia. As I said, organisations provide ongoing support (indistinct) drop off the actual support that has been provided or that is actually accessible. It has a tendency to be more tailored support in the early years, if that makes sense.

**MS SCOTT:** Yes, it does. Thank you. Sven, thank you very much for appearing today and for the written material provided by the council. We find that very useful. Thank you.

**MR TOPP (ADBC):** That's okay. Thank you very much.

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**MS SCOTT:** We welcome people from Ability Options Ltd Self Managed Families, please. If you'd like to have a cup of tea or coffee at any stage, please feel free to go to the back room and get something there, but we will be stopping for a tea break around 11 o'clock if you're the sort of person that doesn't want to miss a second of this. Welcome to the table, Ability Options Ltd, Self Managed Families. For the record, would you like to identify yourself for the transcript and then would you like to make an opening statement please?

**MS QUINN (AO):** Yes, my name's Carolyn Quinn. I'm a parent and carer of two young people with a disability but today I'm here to speak about my son, who has Down syndrome, with very high support needs.

**MR CULHANE (AO):** And my name is Daniel Culhane. I'm a divisional manager with Ability Options and I work with the services that work with people with disability.

**MS SCOTT:** Okay, thank you. Over to you.

**MS QUINN (AO):** Okay. Part of the reason why I'm here is to kind of impart the idea about how different my experience has been since our family has had access to self-managed community participation. Community participation is the part of my son's life which is basically the day hours of involving mostly the - you know, the 9.00 to 3.00-ish kind of time band of his life. We've been involved in that for a couple of years and it has provided an extremely stark contrast to all our other experiences with disability services.

There's a number of things that I'm wanting to stress that I really want out of whatever scheme comes forward; so if I can kind of address a few key things and throw in a few examples. I'm a sole parent carer. As I said, I've got the two children. So there are fairly significant challenges in our household. One of the things that I guess has frustrated me enormously until we started to get access to self-management was the incredibly confining restrictions around choice. For me as a parent - I consider myself quite a competent parent - and yet there have been times in our lives where the state has made choices for us which nobody else have, unless you're in the child protection basket where you've failed to provide adequate care. But the state has been in our life big time. I find that really unjust.

So one of the things I really want to stress is that families, particularly of those who have very high needs who can't make choices for themselves - my son, Tim, who is 21, the level of his capacity for making choices - about whether he has toast or cereal. He can't make any choices about plans, life. It's very simple kinds of immediate-type choices like that. So I'm basically the one that needs to make those kinds of choices in his life. I want to be able to do that and I'm quite capable of doing that but the system frustrates you in being able to exercise that - what everybody else gets to take for granted. So I really want choice about how things happen in my son's life.

The other thing that's disturbed me significantly about the way disability services have traditionally been provided is that there's almost an assumption that service providers make better choices for people than their families do. I think that's intrinsically false. Nobody knows my son like I do. Since we've had access to the self-managed program my son has blossomed phenomenally. He's a person with very high support needs, he's non-verbal, he needs 24-hour care, he needs care to do basic stuff around toileting and things like that but he has a really satisfying daytime hours life of a 21-year-old man; meaningful in lots of ways. I want that for the rest of his life, not just that piece that covers that 9.00 till 3.00 kind of time band of his life; which brings me on to my second key point, and that is that it drives me nuts that my son's life gets chopped up into these little pieces. So what his life looks like between 9.00 and 3.00 is one piece of his life. But if I want to go and get my roots done at the hairdresser, I have to deal with another part of the system to get respite care for him, which is an archaic, paternalistic, phenomenally inefficient system. So there's all these little bits that his life gets chopped up.

So what I would like out of any system that's created is for it to treat my son as my son, a whole person with a whole life, not a 9.00 to 3.00 life and a 3.00 to 6.00 life and a 6.00 till midnight life et cetera. I want it to be a holistic kind of approach to his life. To give you an example about how that affects us on a day-to-day basis, I work. I'm self-employed. I need to employ a carer to be with my son after his self-managed community participation program finishes before I get home from work. But if I then want to do anything else we have this situation where he may potentially have a person with him during 9.00 to 3.00; then from 3.00 to 6.00 somebody else, because a different part of the system kicks in; and then from 6 o'clock till 9 o'clock if I'm wanting to go Thursday night shopping or something, is somebody else. So he could potentially end up with three different people looking after him for one Thursday experience. I think that's bizarre. If we had a holistic system where I was allowed to make choices, I could make decisions about that particular day and what we were going to do and have it all flow smoothly for him. That's a really important thing.

The other thing about - the other example I wanted to stress about the holistic issue is that the system is very service-centric. It's not genuinely person-centred. The way assessments happen is a really good example of that. I spend my life having assessments. For every piece of my son's life that's chopped up into all these little chunks, I have more assessments. For each of the bits, even though they all ask exactly the same stuff, they all need the same information about Tim to be able to provide care - it's crazy. So another thing I would like in a holistic system is that there was like a person-centred approach to that sort of thing so that my Tim has a file of information and everybody uses that instead of me having to do eight different sets for each of the eight players in his life to have the information that they want, to provide the care. So that's really important to me.

The other thing is that it needs to be recognising that people with a disability, including my children, are all different and unique and nothing the system has done has accommodated the fact that it needs to be not a one size fits all. So it has to be able to shift and shuffle and be flexible to the realities of each individual person, not assuming that everybody with Down syndrome is the same, not assuming that everybody with profound deafness it the same. That's what the system is like now. I want it to be flexible so that the support for my children can change as their life changes and as things come up. So for my son, for example for Tim, in winter what he can do is different to what he can do in summer, because he gets lots of pneumonia-type illnesses in winter. It has to be able to accommodate that reality of his life and as things emerge in his life.

That's one of the examples I wanted to illustrate about the self-management. One of the things I was able to do just recently - Tim turned 21 and like any young man he's entitled to the rite of passage of a 21st birthday. Self-management allowed me to do something that was absolutely inconceivable any other time. I was able to employ for a small number of hours a recent graduate that we knew from our extended network who was a recent graduate occupational therapist to do some social education informally with him in preparation for his 21st birthday. It worked sublimely. He got the issue, even though his cognitive capacity is quite limited. He really understood the significance of turning 21 and he had a ball. It was a really successful thing. But no other place except self-management allows you to do that kind of thing. So the system needs to have that flexibility to deal with that kind of life issues.

The final thing before I pass over to Dan - I'm hogging all the time - is that we need to have any system that there is developed, particularly for people with high support needs like my Tim - it needs to consider the context in which that person lives and considers support for the supporters and the carers. So for me, for example, it drives me wild that as a full-time working carer there is zip to support me to be able to continue to work. My only alternative is not to work, to go on one of the Centrelink-type benefits and take my family into poverty, which I'm not prepared to do. That's a major frustration to me. The other thing is that the current processes, the procedural-type processes, those repetitive-assessment processes, the cumbersomeness of the system, how it chops up Tim's life - basically where it has left me is that the greatest source of stress in my life is dealing with the system. Way more stress comes to me from dealing with the system than it does to managing Tim. He's a lovely young man, I like spending time with my son, but the system is a killer. I've spent huge amounts of time form-filling, correcting issues, all of that kind of stuff.

The wonderful thing, which we might segue to Dan - the wonderful thing about self-management, which is just that piece of Tim's life, is that that doesn't happen. I'm in charge of it all. I make all the choices. I make all the recruitments, the selection. I choose who works with him, how they work with him, what they do with him, how he spends his time. There's information and support but I am absolutely in control of that ship, and that's what I want for the rest of his life.

**MS SCOTT:** Does it come as - you've said it's 9.00 to 3.00. It comes as hours, it comes as an amount of money, it comes as a range of services?

**MS QUINN (AO):** It's a budget based on an assessment of needs.

**MS SCOTT:** Yes.

**MS QUINN (AO):** So Tim is assessed as having very high support needs, which has a dollar value to it. But you also have to comply with the added requirements to have 30 hours out of that - 30 hours of support for Tim from that budget allocation. There's rules about how some of that happens. You have some bits of flexibility but it's basically his daytime life. It's not the rest of his life that that deals with.

**MR CULHANE (AO):** Thanks. I agree with Carolyn. Some of the points I'd like to make, I suppose, are from the paper that we put together in consultation with Carolyn and some other families that have been self-managing with Ability Options over the last couple of years. It's an interesting position to be in, I suppose, for Ability Options in terms of a service provider of disability services of a wide range in what's, I suppose, the traditional disability service system of a range of accommodation support needs for people ranging from people at risk of exposure to the criminal justice system to people with mental health issues and dual disability as well as drop-in support - models of support people, employment, case management - and to compare that with a self-managed individualised funding approach. It has definitely thrown some of the challenges across, I guess to me as a manager, and Ability Options to be serious about person-centredness in the services we provide; much along the points that Leah Hobson made from the Australian Federation of Disability organisation and also, I think, some points made by Sven.

In terms of what we've put forward, Ability Options and the families and people with disabilities that we consult with around the services we provide, and what it has got to offer the disability insurance scheme, a couple of quick points. I'd say that it's a holistic assessment of what a person needs. Carolyn's made those points very clearly. I started a consultation with some of our core families who have been doing this for a while about, in terms of New South Wales, how we move forward with the concept of self-management. In my head before I went to the consultation I thought, "We've got to work out what are the different service types that we have to offer people." The first thing that people said to me was, "We don't want a range of different service types.  We just want to be considered in a holistic way."  The bridge now is to change the service system to accommodate people in a holistic way.  I think that point is well made.

The power is given to the person with a disability and their family about what happens.  Real purchasing power, they manage the budget, they do the plan.  People who require a level of assistance get that, and that's determined.  People who don't need it, don't.  They employ the staff.  They select them and they select people that work because they know what they want and they know what to do and they get a really quick sense of who works and who doesn't.  I might also add that the model that we've been using has got a level of case management support.  We're currently looking at tinkering with that.  Some people would prefer, like Carolyn, to move to self-directed payments and they know what's required.  Other people need a little more assistance.

In that way we're pretty proud of the fact that in coming up to three years of the self-managed project we haven't had an industrial relations issue through that to this point, touch wood.  But I think that's - in the way that it's gone out and it's also, I think, a credit to the people who are managing their own funding but they have a pretty good idea of what they want and what works and what doesn't.  You get greater outcomes by virtue of the fact that the service is run by the people who are investing in it.  There's an incredible level of transparency and perhaps - the statements that we put out to families account for every cent, and people with a disability, of where it goes and why and it's in line with the plans they've done.

Independence and socially valued roles.  Again, some points made by Leah Hobson.  People are actually - and particularly in rural areas as well, people just access the services they want and they purchase the things they need.  They don't have to be constrained to the disability services system.  This is a huge advantage. It's also - people - you know, one of the parents came to me and said now her daughter volunteers at the local real estate agent.  She also did voluntary work at the local post office.  When she is walking down the street her mother feels a little bit like a passenger walking along next to her as people say hello that she knows and she works with that previously she had no contact with.  Again, I think that's a real challenge for our organisation to look at the people within our services and people in group-pay models that have very limited social networks.

I guess that's the point of broader social networks, some points again made by Leah Hobson that a decent assessment of somebody's resources and types of supports they need looks at the informal supports and the formal supports they have.  There's great benefit to that.  A lot of the people in the self-managed program in terms of - if the government was to look at value for money that they get for the money they invest, there's a significant amount of hours that are pooled in by people that they know that actually have a formal role now to come in and work with them in their lives and also some people in the broader community that get a bit of a licence to come in and get involved.

Just on a couple of points that were mentioned yesterday, I suppose, around - Michael Bleasdale mentioned the HASI initiative, the mental health and housing initiative.  Ability Options is also involved in DHASI, another acronym, but - Department of Housing and Support Initiative - where we've had a partnership with a community housing provider in a local area.  ADHC has provided the funding, and they provide referrals of people with disabilities who require up to 35 hours a week support with capacity to provide 50 hours for people if they have emergency situations.  It has worked fantastically.  We've done that in the Wingecarribee area.  People are maintaining their tenancy with the Department of Housing.  Community housing provides the bricks and mortar and we provide levels of support for people to just maintain their tenancy and participate in the community any way they would.

It's a good point that's made about the difference between availability of social housing in different states.  It's also available to different levels in New South Wales.  We started that program at the same time as another organisation started it in the Macarthur district, and they had great difficulty getting access to housing, so they had great difficulty getting anything done.  I guess the point I'd make on that was if you did make recommendations around housing it's important to make the resources available to housing to follow through on that.  We made this initiative work but the housing provider was basically told to just provide more places for their existing list of people.

Just a quick comment on eligibility in terms of - I concur with, I think, the majority of people that have said to you about looking at the definition of disability in line with the UN convention on disability.  I think a broad definition of disability with accurate assessment of what people need and a holistic approach - there are informal and formal supports combined with accurate allocation methods that are linked to those is what is key.  I know the I-CAN model has been presented to the Productivity Commission - - -

**MS SCOTT:**   You're well informed.

**MR CULHANE (AO):**   Ability Options also - we use I-CAN as well and endorse that in terms of a model that really looks at what people need in terms of intellectual disabilities and types of support.  Thank you.

**MS SCOTT:**   Carolyn, thank you very much, and Daniel.  Daniel, would your organisation support the option of going to funding packages where the money was allocated directly to the person with disability or their families and then you received no block funding?

**MR CULHANE (AO):** Yes, we would. I think in terms of that decision it's really around looking at, I suppose, the accountability for that funding and assessing a person's capacity to manage that. I'm sure there's broader philosophical debates about to what level people should be accountable for funding and there's different approaches, Australia and overseas, whether you just pay people and let them go and spend the funding. I think we have examples of people who could have direct funding. There is acknowledgment, though, I think, within - I'd be interested in your comments, Carolyn - but I think there's acknowledgment within people that want direct payments that there still is a role for an organisation to provide insurances and administration, for people to assist with that.

**MS SCOTT:** I understand that and even where it operates overseas we still have very high levels of people effectively handing over responsibility of those funds to an organisation, but at least it's their choice rather than having - sometimes we've had people present to us individualised person-centred funding but actually it goes to the organisation and then the organisation chooses who gets the personalised package. I guess I just wanted to clarify your views on that. Carolyn, there's something you stated that I wanted to come back to and I'll just check my notes a little. You'd envisage that you'd have perfect capability to look after a total budget rather than just the 9.00 to 3.00 budget?

**MS QUINN (AO):** Absolutely. I've run a business for 20 years; I can easily do that.

**MS SCOTT:** I know the Victorian system, I've had someone show me the forms and so on in Victoria, there was half a dozen headings. What's the level of red tape and compliance associated with your current arrangements? Is it still very intense in terms of accountability or do you think it could be reduced or increased? I mean, what's your view on - - -

**MS QUINN (AO):** Are you talking about with the self-managed part?

**MS SCOTT:** Yes.

**MS QUINN (AO):** It's less than any other part of Tim's life. So what we have to do is - which works anyway - set quite clear outcome-based kind of goals and plans and have strategies for how that's going to be achieved and the costs associated with those strategies, and all of that has to be planned out. Then you go forth and do it, and then the Ability Options does all the back office to keep the accounting of those dollars. That's what works at the moment in the current system and every penny gets accounted for. In terms of the outcomes for Tim, there's regular reviews conducted about, "Has Tim achieved outcomes that we'd planned and used the funds to do." My experience amongst the parent group in self-management is that they fly way past the outcomes because you can weave things in that you just can't do in any other situation.

**MS SCOTT:** You talked about Tim blossoming. Could you talk about how his experience is now very different from what it was before? I understand your experience is different but could you explain what's different for him?

**MS QUINN (AO):** Well, he's not kind of clouded by the societal thing about being a passive recipient of service. It changes the agency of his life completely. So, for example, Tim has always liked the garden, outdoor stuff and even though he's got quite limited abilities there's some quite discrete skills that he has. He's great at raking and sweeping, for example. So one of the things I've done is create a little, mini service - entrepreneurial service - for Tim in our immediate neighbourhood where he does things like raking and sweeping for elderly, housebound people in our immediate vicinity. It's not via the service, so the elderly person and their family is relating directly to Tim. He feels proud. He knows they need him to sweep their path and he feels very proud when he's done that. It's not the token stuff.

Because it creates relationships for him, it's bringing in all these other benefits. So, for example, because he's working with elderly people, one of his customers died. She was an elderly, 90-something-year-old woman and she died, and the learning he got out of that process was phenomenal because her family appreciated what Tim was doing for her and they included Tim in the funeral and all the process and he got phenomenal learning out of that - life learning. Those things keep happening all the time. The experience about walking down the streets of where we live and people saying, "Hello," and having a chat - people I have no idea who they are but they clearly have a relationship with him, and I love that. I really love that he has a life of his own as a 21-year-old man and that his mother doesn't know and have every bit of it.

I'll give you an example of how some of that turns into really phenomenal outcomes for him. Tim has very limited cognitive ability and all through his life, through the education, through everything else that we've ever done, he has never initiated anything. So he's never had an independent thought, "I will go and do this now." Of recent times, now that we've been doing the self-management for two years, he's started doing things that were just not even there. So he'll just decide to get up and go and put his pyjamas on and go to bed, all by himself. Those things were just unheard of. I get really excited about that because those are things that will make huge quality of life differences for him in his future, whereas previously that whole thing of being a passive recipient of service, the learned helplessness thing is incredibly powerful in his life. He's got the idea that he's in charge of his life and it's starting to pay dividends like that, that are phenomenal for a person with his level of cognitive disability.

**MS SCOTT:** Carolyn, I'm on a roll; I'm going to have to give David less opportunity but here we go.  Are you now confident that you've got this package now for the rest of time or is it a pilot, is it going to stop in a year's time?  Do you have certainty about the arrangement?

**MS QUINN (AO):** It was a pilot but it's now been established as an ongoing program.  So as much as ongoing state government programs ever are, it's permanent, yes.

**MS SCOTT:** I want to go back to accountability and if you've got to send us an email later, that would be fine.  You said it's so much better than what you're used to but in some ways it's a bit like the other things you've talked about; maybe the point of comparison is not a good one.  Some people have pointed out to us that the amounts of money we're often talking about is quite small but the level of accountability is extraordinary compared to the risk associated with other sorts of government funding.  Having to account for every - I think both of you talked about accounting for every penny or every cent, well, that doesn't happen everywhere; people take a risk management approach.  Compared to the level of risk associated with this, thinking about your business experience rather than what you're used to in the disability sector, is the level of accountability appropriate, over the top, insufficient?

**MS QUINN (AO):** In the self-management bit I don't find the level of accountability burdensome.

**MS SCOTT:** Is it appropriate?

**MS QUINN (AO):** You could probably loosen some aspects of it slightly but I think it actually - I find it quite helpful keeping you on track.  It gives a little bit of structure in some respects.

**MR KALISCH:** I just have one question and that was around the micro business that Tim has.  We've heard a number of examples as well of where there have been, I suppose, innovations that parents have worked with their kids.  Certainly you're in a unique situation having your own self-business and can set that up.  Do you think there are many more opportunities for people to operate and run micro businesses with support from possibly external assistance if they don't have that family support?

**MS QUINN (AO):** Well, I don't think you actually need to have a business head. It's really about the reason why what Tim is doing is successful is not because I'm a businesswoman but because I thought, "What does Tim love?  What is Tim good at? Who needs that?" and just matched it up.  I don't think you have to be a business person to be able to do that; you have to be a person who really knows your son or your daughter and what their interests and abilities are, and capitalise on it.  That's all we've done.  All we've done is match what Tim can do with somebody who needs that. I think that part of the power of this self-management - and lots of the other parents in the program talk about very similar things, their young people are doing a huge array of things - is that thing about looking at the strengths and matching that up with what is out there in your community and creating this mutual benefit. Part of the reason why what Tim is doing works so beautifully is that it's genuine need on both sides of the deal. They're getting something out of it, Tim is getting something out of it, and it works really well. You don't have to be a business person to do that.

One of the things some parents need, and we've talked about this amongst the parents at Ability Options, is the back office functions. If the funding comes to me I probably would choose to purchase the back office in some respects because I like to separate my recruitment selection and supervision role of the staff from the payroll, workers comp - I like that Ability Options looks after that. So in that sort of thing I probably would choose to buy that bit from an agency, just because I like that separation. It works well for us and the people that are supporting Tim.

**MR KALISCH:** So that comes down to choice again about how those things are structured and what you purchase, what you do yourself.

**MS QUINN (AO):** That's right. I would like the idea of it being like a menu and you could say, "For our family we need this, this, this, this, this, this and I'll buy that bit over there."

**MR KALISCH:** Thank you.

**MS SCOTT:** Your presentation was very clear at the start and thank you for making it so clear. I wouldn't mind just exploring one or two other areas. Could you talk about, if you feel comfortable, long-term accommodation needs for Tim, maybe even after you die, and what you would expect a scheme to provide or what you think you should provide relative to that?

**MS QUINN (AO):** Well, I've already started the plan on that one and I kind of have a 10-year plan for Tim to have a home of his own. I've purchased a place that will be suitable for him to have as a home of his own and I'm paying that off, but I'm really desperately hoping self-managed accommodation comes in. My aim is for him to have a home of his own by the time he's 30 and I really hope we have self-managed accommodation support by then because I really want the value that he gets out of the self-managed community participation to spill over into his other parts of his life. What I would like is for that to have the same degree of flexibility and choice as the self-managed community participation has.

What I have in mind is - because my Tim, even though he's nonverbal he's a very social bod, he could not live alone and be happy, so I'm kind of spending my time looking for potential people that might be in Tim's life in that long-term way, and there's some emerging.  I cannot possibly finance 24-hour support.  There's no way in the world I'm going to be able to make that happen.  I can give him a home, as in bricks and mortar, but I will need to have hours of care.  Whilst I want Tim to have a home of his own and live with people of his choice, not necessarily people with a disability, and I want that, because of Tim's level of need I will need to have paid support because there are things in his personal care that I wouldn't want a flatmate to be the person who does that kind of stuff for him.  So that's what I will be looking for; the capacity to recruit and select and place hours of support into support housing in a home that a trust fund for him actually owns himself.

**MS SCOTT:**   Does Ability Options have any interest or a desire to get into that sort of arrangement where, I don't know, someone else might provide the housing but you are the broker to, not necessarily choose the flatmates, because that would be inappropriate, but provide a sort of a background support in terms of organising hours of care or maybe guided decision-making if the parent isn't available?  Are you into that space?

**MR CULHANE (AO):**   Yes, absolutely.  Part of the logic of forming a consultation group with Carolyn and some of the other families who have got a bit of experience now is trying to nut through the difficult questions that we have to face.  It's early days in New South Wales but just recently ADHC has released flexible accommodation packages.  I'm working with a family at the moment on a flexible accommodation package.  At the moment we're sort of encountering those hoops between the person self-managing a CP package.  You know, they've got a flexible accommodation package, and every funding package from a government has got conditions and things, so it's a bit of a test case for us.  It's early days but we're more than happy to develop those ideas.

**MS QUINN (AO):**   I just realised I didn't quite respond to the bit about when I die.  What I have in mind in my plan is that in my will I have a panel of three people who will pick up where I've left off being the person who makes the choices, but maximising Tim.  So there's kind of criteria for the exercise of those choices; that it's all about him having the lifestyle of a person his age, whatever that age is, you know, when he's 40 or 50, or 30 of whatever it is.  I wouldn't want to hand that over to a service provider, I would still want it to be people I choose to hand the baton to who know and love Tim.

**MS SCOTT:**   Carolyn, one last question - morning tea time has just been refused as a result.  We've been asked to consider the design of a scheme and there's all sorts of options available, and clearly you've told us a lot about parents or the individual being in control of their package, and thank you for the other information.  Would you have it as a national scheme with national standards?

**MS QUINN (AO):**   Yes.

**MS SCOTT:** Would you have a state's disability services manage it or would you, as much as possible, have the money managed through the individual parent making decisions about whether it goes back to a service provider or not? I just wouldn't mind your idea of a design. Would it be going through ADHC, would it be going directly to you, would it be going only to service providers and then dished out to you? How is the money going to get distributed?

**MS QUINN (AO):** My preference is to chop out all the middle men so that it comes direct to me and then I have the choice to say, you know, "I'm becoming an elderly carer so I would like to hand over this bit to the state disability system," or, "I would like to hand over this bit," but I would still like to have the choice. One of the huge frustrations I have with the current respite system, for example, at the moment is that funding goes to the organisations. I don't even get a choice about which organisation I deal with in respite. It's like zero choice - zero choice - and it keeps changing, so I have to re-educate them all every time. I definitely don't want any of that. Chop out all the middle men and let me make the choice about which bits I hand back to service providers.

**MS SCOTT:** Thank you very much.

**MS SCOTT:** We now invite to come forward Mark Sheehan from Allowance Incorporated. Welcome, Philippa and Mark. For the transcript, please, could you state your names and your organisation, and then would you like an opening statement.

**MR SHEEHAN (AI):** My name is Mark Sheehan. I'm from Allowance Incorporated.

**MS GORMLEY (AI):** I'm Philippa Gormley. I'm a user of the services that Allowance provides.

**MS SCOTT:** Thank you.

**MR SHEEHAN (AI):** Well, I should do a little bit of an introduction. I'm a CPA in public practice at the moment but I'm also the general manager of Allowance Incorporated. I'm also a teacher with OTEN, New South Wales and the main specialty I have there is people with a disability. Now, as far as Allowance Incorporated is concerned, it was formed in 1992. It gets funding under what DADHC calls the cooperative model. From my understanding is that we're the - Allowance is the only provider in New South Wales that is actually under this model. I don't know that - it might also be the only one in Australia, from my understanding, but I don't know of any other people.

Now, the great thing about Allowance Incorporated is that it's user run and user defined. When it was originally set up the people that set it up were all quadriplegics. One of the criteria that they set up was that all people that do come on board as participants were to be quadriplegics, but that has expanded or that has changed during that time. We're in the process of changing our constitution, but we have been taking on people with other disabilities aside from quadriplegia. Now the main criteria that we look for with people that are coming on board is that they can manage their own affairs. Once again, we've even been a little bit flexible with that in that we have taken on people that have an acquired brain injury or other disability and been largely cared for by their parents, mother, father, husband, wife, whatever the case may be. They're unable to look after their own affairs but certainly their parent is doing it.

I suppose I speak from a glowing point of view. I think Allowance is the best thing since sliced bread because it gives our participants a lot of the benefits of the self-funding model without a lot of the unnecessary bureaucracy and responsibilities that go with the self-funding model. How it basically works is all our participants - we act in New South Wales and ACT. Funding in the ACT is a little bit different to what it is in New South Wales. People receive an attendant care package in New South Wales which allocates them a certain number of hours, 35 hours, 28 hours, whatever it is, we divide by seven. That's the number of hours that they're allocated each day. They're allowed to use that number of hours each day. They hire and fire their own employees. It's not mandatory that they use - if they don't want to they don't have to have employees. They can use an agency if they like or they can have a combination of both.

We run a bank on a fortnightly basis where if somebody doesn't use the number of hours that they're entitled to they can use them in the next fortnight. Some people - all those hours have to be acquitted back to ADHC at the end of the year. The maximum number of hours at any one time, I suppose everybody knows, is 50 hours. We don't really go through and start getting people to use their hours if they've gone over, but certainly we don't have any choice at 30 June, so we've got to go through and acquit all the money back to ADHC that hasn't been used as at two weeks ago, 30 June.

Some of the support that we provide to people - as I say, they're allowed to hire and fire. We provide them with newspaper or Internet advertising. We pay for that. They actually do the ad, say what they want to have in there. They run it past us first just to - for us to give it a bit of thought. We employ an occupational therapist to go out and visit - well, I've only employed her from the beginning of this year but the intention was for her to go and see everybody within the space of two years but it looks like she is going to be able to go and see everybody within 12 months, because ADHC is - well, hasn't been able to go through and provide that sort of assessment. Well, it hasn't been able to - just from my perspective it hadn't been able to provide that type of assessment on that type of an ongoing basis. So she should be seeing everybody within 12 months, just to see how the procedures are. She assists with training of the attendant care workers, just with the way they go about their day-to-day activities.

We also employ an OH and S person to go out to assist - I guess as an assistant to the occupational therapist and also more hands-on. We do - one of the things we've just taken on in the last month or so, we do what they call electrical tagging, to go through and check that people's electrical equipment is not going to kill them or anything like that whilst they're there. What they also do - as I say, they're hiring and firing, but on a fortnightly basis they submit all their time sheets to us and we arrange to pay all their carers for them. We also pay their superannuation. We get all our participants that are not using agencies to register with the Australian Taxation Office with a PAYG registration so as they can withhold the tax from their salaries. We lodge their instalment activity statements for them on a quarterly basis, in case of need. We arrange all their workers - pay all their workers compensation. We pay all their superannuation. We pay 15 per cent superannuation to all the people, which is well above award. So they can generally attract people more readily than what the market is able to do. We pay well above award wages for all our people. I guess - what else do we do? That's pretty much it.

Generally our funding - the funding that we get from ADHC, from my history - I've been the accountant with them for about four or five years. I've been the manager for about the last 18 months or thereabouts. But my history in that time is that generally of all the funding that we get from ADHC or from Disability ACT, we remit about 10 per cent back to ADHC every year because of the unused amounts. We've got about three and a half employees on a full-time equivalent. We pay something like 400 employees every fortnight and something like 30 agencies every fortnight. I'd like to think we're one of the most efficient organisations around the place. I don't know if it has come through but I'm very proud of Allowance. I've had people that are members or that are participants that have come to me, more than one that are quadriplegics, and they have said that, "Allowance is the best thing that's ever happened to me." So that's where we are.

I think you could say that's a good way to be dealing with people in the future. I think it's just a very - because as I say, we have three and a half full-time equivalents there dealing with that type of transaction. I think that's about all I can think of. I've done a bit of - in this paper I've done a little bit of a funding model going forward for the national disability scheme.

**MS SCOTT:** Thank you.

**MR SHEEHAN (AI):** Including some costings - well, not costings but income projections on there. I have a few thoughts as to the way the - what do they call it - the national compensation scheme should be set up and run. I have a bit of a history in that I have set up some insurance companies in the past.

**MS SCOTT:** I wish John Walsh was here today. I'm sure he would love to talk to you about that. But maybe what we should do is we'll ask a few questions about that and we'll put you on notice to expect a phone call at some stage. I'm sure he'll have an interest in that. Philippa, do you want to say something now?

**MS GORMLEY (AI):** Yes. Well - yes, sure. I'm a user of the system. I'm on a 35 hour package. I'm a barrister and have been for many years. I ended up in a wheelchair as a result of MS. I have no cognitive problems but I do require assistance with all aspects of daily living such as making a cup of tea and dressing, all that sort of thing. The attendant care program gives me 35 hours a week and through Allowance Inc I can employ people either directly or through an agency. I use both approaches. What the system gives me is absolute flexibility and it gives me my choice. I don't have to say how I use the 35 hours a week. I can save them over a period of time. If say my husband is going away I can collect it and use it appropriately, so flexibility is very important.

With regard carers, employment of - direct employment of carers is probably the best way to go except that - where I just employ somebody for a solid period of time during the week. However, because I am so severely physically disabled I need an hour in the morning for personal care and showers. I also need an hour in the evening. Those hours are quite difficult to fill. I live on the North Shore and I understand that labour is very difficult. What an agency allows me to do is rely on their bank of staff in the event that staff is not available or my person is sick. The carers that I use, both through the agency and directly, are often mothers of children who really just want some casual work, so they don't want to enter the workforce; older women who also don't want to enter any permanent workforce; and students, often from the health care industry, say nursing students or OTs, physiotherapists.

One of the advantages I have found - before I had the attendant care package there was absolutely no support for me with regard to rehabilitation. My problem was that I had a disease rather than an injury which was compensable, you know, such as a car injury. So I would often be sent - suggest that I go to the MS Society. Well, I personally sit slightly outside of the MS Society because although I look dramatic I have a fairly steady unusual form of MS and so work quite well cognitively and other ways. So what the MS Society provided was for more severely - I say more severely disabled, but a different type of disability to me. So as a result for years I went without any rehab, for many, many years. It was really quite inappropriate, I thought. It certainly wasn't through lack of me trying to get in there. It's just that as soon as I said MS they said, "Well, sorry, spinal cord injury only."

Just generally I say that people with disabilities who have the ability to organise their carers would benefit and do benefit from this model, the attendant care package model provided through Allowance Incorporated. Flexibility really is its most important thing and ideally it should be offered on a national basis because at the moment it's only offered in New South Wales. I know that portability provides real problems. So for example, if I wanted to travel up to Queensland even for a short-term visit, unless I can find a carer up there I'd take somebody with me. Certainly I know that other people have attempted to move out of New South Wales to live somewhere separately and have had to choose to give up this particular package or - to give it up or not to move. That's just inappropriate. This allows me to be a productive member of society even though I am unable to do some of the most basic things.

**MS SCOTT:** Thank you. The limitation on New South Wales and the ACT is because your funding comes from those two governments as well as the federal government. But the New South Wales and ACT governments clearly won't fund anywhere outside those two areas.

**MR SHEEHAN (AI):** They will, but they'll only allow maximum 12 months for people to live in another state before they have to get funding from within that state. I guess our chairlady who was living in Queensland was basically forced to return to New South Wales because she wanted to have the Allowance model. It wasn't a decision she had by choice but that was just - she wasn't able to have the same options that she has with the attendant care package or with the Allowance model.

**MR KALISCH:** That 12 month portability is something that we sort of have been made aware of more generally across disability services, so it's obviously a national agreement for 12 months' portability.

**MR SHEEHAN (AI):** I mean I would love nothing better than to be able to go national. One of the methods that I thought I had in mind was to become registered or get accreditation with the Attendant Care Industry Association. But Allowance only employs - as I say, Allowance only employs four people. Allowance participants employ - well, during the course of the year they'd be employing close to 1000 people but the attendant care industry won't let us do the accreditation because we're not employing our own carers. So that's a bit of a downfall.

I'm looking to get onto the Attendant Care Industry Association with a view to changing their rules there. That's one method but of course if we could go national - we did use to have Queensland funding. We only had one member up there but they used to put us through the hoops and make us go through the whole - we go through the accreditation process down here and by and large the ACT government accepts that, because all our accounts are audited by an external auditor and we go through also the ADHC accreditation process. Now, we've never had any problems with the ACT. I have actually had one of the participants down in the ACT say that he has been approached by the ACT government with a view to them making the Allowance model much more universally available down there. So yes, portability is a big issue, I guess.

**MR KALISCH:** Philippa, would you see a national - sorry, I've got two questions. One is do you see advantages in a national scheme being able to then utilise the funding arrangements flexibly across state borders?

**MS GORMLEY (AI):** Absolutely. It seems a shame - this truly is a very good model. It just seems a shame that it's not offered to all Australians, really, for a start. Also it means that - say my husband and I, if we chose to retire, at the moment we're restricted to New South Wales because the reality is he's a bit older than me and it would become - I would become quite a difficult burden if we say moved up to Queensland, which we have family up there. We might choose - we might want to do it but we won't be able to.

**MR KALISCH:** You talked about having the flexibility or to some extent the safety of the backup of Allowance Inc or the agency providing the staff.

**MS GORMLEY (AI):** Yes.

**MR KALISCH:** Are there other advantages of the model? What are the key advantages for you?

**MS GORMLEY (AI):** One of the key advantages of Allowance Inc is that I am able to choose my employee. It's quite a personal thing, of course, because you're - obviously it's a personal thing. But I don't have to worry. My occupation is - quite different to what Allowance Inc offers. I don't have to worry about my payroll tax or any of their income tax or insurance, all that sort of thing, all the paperwork is done. So I probably wouldn't have the time to do it myself. If I were to just employ them directly then I would probably have to pay an accountant or somebody to do that sort of thing for me, because it's just quite different to what I do on a professional basis.

**MR KALISCH:** Does it work flexibly with your job?

**MS GORMLEY (AI):** Absolutely. The flexibility and in a way - the staff that I have available, because of their hours, and they like to be a bit flexible means that I can ring up at the last minute and say, "Can I have somebody for an hour," or, "I need to go to this court or that court," because sometimes there's movement during the day, because I can drive but I can't get in and out of the court myself. I have yet to find somebody who is happy to help me do that. I make them a bit nervous, really, so I really do need a carer to do that sort of thing for me.

**MS SCOTT:** I just want to check on the hybrid model because some people have expressed an interest in having their own employees but then it they don't turn up, you know, they can't get out of bed. I just want to check, does it work like this, that Philippa is able to - maybe a question that - go to you, Philippa. You're able to engage your own person but if it turns out they're ill or some other responsibility means they can't attend, you have the confidence of a backup. Is that how it works?

**MS GORMLEY (AI):** That's why I use an agency.

**MR SHEEHAN:** That's why you use an agency. But if you employed direct - sorry, if you employed just a person who you know and have good regard for and they couldn't turn up, that wouldn't give you the safety protection of a backup person?

**MS GORMLEY (AI):** Well, for me I live with my husband and until recently I had always had children around, who are now adult. But in any event for me I would always have two direct employees, so that if one can't do it, the other one can.

**MS SCOTT:** Okay, that's good.

**MR SHEEHAN (AI):** I always encourage all the participants when they come on board, particularly when they're new, to say, "All right, the more the merrier, just in case you do have such a contingency," that if somebody does get sick or goes and leaves or somebody gets sick and leaves, then you have a third person you go to. Of course, they want to get as many hours as they possibly can, but at least if you have some people there and they're getting 35 hours a week between them, that's a reasonable income, it's $80,000 a year between three people and it's casual work.

**MS SCOTT:** Thank you for the inclusion of figures in your material to us today about your overheads because we've been gathering material about overheads over time and it's good to be able to make comparisons. I have to say at first blush this looks like a very low-overhead model. Should we now turn just briefly to your ideas about how it can be funded. Some of the proposals we have seen at earlier times and other places, so I won't go to the ones that are not unique. But the one that I think is unique is the idea of introducing a registration scheme for all pushbikes. Could you just briefly address that, Mark, about why you think that should be in the funding model.

**MR SHEEHAN (AI):** I guess the main reason, as a distracted motorist coming to Sydney on a Saturday morning taking my kid to sport and driving down the Eastern Distributor and having to give up a lane to pushbike riders - I don't know if you're aware about 12 months ago there was a major accident where there was a bit of road rage and some people on pushbikes suffered very significant injuries as a result. You hear about the injuries to people happening all the time and quite a few without actual participation. One of my very close friends fell off a bike about a month ago, six weeks ago and he was in a coma for four weeks and now his mum is having to go through and take him everywhere. He's had to give up his job for a while. He was wearing a helmet. We know these type of injuries happen.

I'd like to think it's a win-win situation because there's a lot of hostility towards pushbike riders within the Sydney CBD because people - the bike riders, couriers, what have you - tend to ignore the road rules and they know that there is a very little a policeman, even if he was able to catch them, would be able to do about it. If there was to be a registration in place - that's why I don't think there would be much hostility towards it because if you go and sell that to a kid and say, "Well, it's going to cost you $25 a year to ride your bike on the road but you're going to have complete coverage, you won't have to go and fight for any compensation. If you do have a head injury, you won't have to fight for it," I think that's a fairly cheap rate to have to go on.

**MS SCOTT:** Okay. Thank you very much, Philippa. Thank you, Mark. Mark, will you be making a formal submission or will this constitute your submission? I don't mind, I just want to get a sense of - - -

**MR SHEEHAN (AI):** I could probably meat it out a bit.

**MS SCOTT:** We would welcome that. This is a great introduction, but if there's any further material you'd like to provide, we'd be most interested.

**MR SHEEHAN (AI):** I would do. The only problem was this was done in May and I'm still the accountant for the place so I'm doing all the - - -

**MS SCOTT:** You're juggling everything. Thank you very much.

**MR SHEEHAN (AI):** Thank you.

**MS SCOTT:** This is the long-promised short break. We might just take 10 minutes and be back here at 22 past. Thank you.

**MS SCOTT:** We'll resume the hearings now, so thank you very much. Dianne, thank you for coming to the table. I understand you're representing yourself.

**DIANNE:** Yes.

**MS SCOTT:** Thank you for your submission earlier on in the piece. Would you like to just make a few opening remarks and then if you're comfortable, we might just then go to questions.

**DIANNE:** Sure. My background in relation to disabilities is that I have a 10-year-old son who has severe disabilities and requires constant care. Constant care, I saw from your issues paper, is a person who can't be left for an hour by themselves because they would have some problem. My son can't be left for a minute, and I mean that literally. So his level of support that he requires is extraordinarily high. My submission is to first of all simply say that the system of disability support is terrible, totally broken, absolutely inadequate and, if nothing else, I would hope that the Productivity Commission's work can lead to the introduction of a system of care and support that will focus on the absolutely most needy in our community. While not to understate the serious needs of everybody with severe and profound disabilities, if you could focus on those requiring constant care because it is impossible to provide extremely high levels of support as required by certain people who require constant care. It is actually impossible to do that just with family carers.

The current policy of just requiring people, even with the most extreme needs, just live in the family home for ever is so flawed simply because it is physically impossible. So families like me are forced to renounce our children, to make them homeless because there are not services we require. I know that I will have to renounce my child within the next decade and I would hope that your work will avoid that.

**MS SCOTT:** Thank you for that. We might now just use a question and answer approach - - -

**DIANNE:** I'm happy with that.

**MS SCOTT:** - - - to just go through this and thank you for making your submission so clear. You don't favour means testing and I think that's on the basis there is already a substantial amount of costs associated with each family having - - -

**DIANNE:** I suppose I favour simplicity. Once we start getting all these layers of testing and how much family support do you have and where do you live, right, the whole thing becomes so murky and we get into the same sort of problems that we see with the current system of - all the money seems to disappear on bureaucracy and there's no service coming out at the end.

**MS SCOTT:** I think you were here for some of the earlier testimony. You clearly are in support of centre-person assessment and control of the money being in the hands of the individual or the parent or guardian. Is that right?

**DIANNE:** Yes, and in my submission I suggest that actually a formal advocate role should apply for those who are unable to make informed decisions and communicate them. Because so many decisions do need to be made, it really should be formalised, I think.

**MS SCOTT:** Do you see a national scheme having national standards with the money paid directly, in your case, to you?

**DIANNE:** Yes.

**MS SCOTT:** Would you then take responsibility for hiring employees?

**DIANNE:** Yes. The models that were talked about by the last two or three speakers seemed fabulous but they're tiny and they need to be expanded. All choice should be with the user or their advocate if the user is unable to communicate their decisions and then the user can choose which services they wish to provide. Most service providers currently seem to have been way too protected from competition to date and provide a very poor quality service and the absence of flexibility reduces some services to nil value and a waste of money left and right.

**MS SCOTT:** Would you see a role for state bureaucracies in the system as you envisage it?

**DIANNE:** No, I have zero confidence in ADHC based on my 10 years of dealing with them. Cut them out as far as you can.

**MS SCOTT:** Who would undertake the assessment?

**DIANNE:** I would imagine that there would be some body set up at a federal level to administer a system of care and support and that individuals could frankly go to a GP or there would be specialists - medical people frankly. I think there would really just be medical testing about physical abilities or intellectual disabilities which doesn't really need to be in the hands of the government, really just a Medicare number for these types of tests could exist, I would imagine because it's a medical test and it should be done once and never done again because it should try to identify whether a disability is permanent and if it is permanent, then it doesn't need to be reconsidered other than if the individual was required to make some disclosure if their circumstances changed significantly in future. One-off testing should be a no-brainer.

**MR KALISCH:** You talk about, I suppose, the range of services and the difficulties with the services that you receive at the moment. If you were to actually design the services that would meet your needs and your son's needs, what would they look like?

**DIANNE:** Supported accommodation to start with, not necessarily full-time or forever. But the fundamental problem, I think, with our current system is the total collapse of the public service that is supposed to be supported accommodation provided for people with disabilities. It is such an important issue that it outweighs everything else because - I would look for a shared care service frankly like - even though my son is 10 we could probably keep him living with us until perhaps he's 15 on a part-time basis but once he's physically bigger than me - I have to physically restrain him often, constantly almost in public. It becomes just impossible but he sleeps through the night. We could save the public purse a lot of money by having him sleep with us all the time but it all comes back to flexible arrangements which have a lot more public funds behind them than is currently available.

But that flexibility would allow me to buy in services for him during the day, at the times that we need them, on the days that we need them in a manner that he can access, whereas currently we're offered respite which is inflexible and inappropriate such that I have to refuse it or accept it and say, "I accept overnight respite for my son," and I feel guilty that - I know that there's a lot of waste involved but I accept it for a day and I pick him up after three or four hours because he can't stand to be there more than three or four hours and his needs are so severe that if I left him there longer it would make the next couple of days for me so much harder that the value of having had a break for a few hours is totally undermined.

So, you know, I have to partially use services and cause an enormous amount of waste in the system because of lack of flexibility. So a flexible service that would allow me to purchase supported accommodation when he requires it in a very unusual type of way, really, because I would like to be able to take my mainstream son on a holiday for a weekend so that for a short period of time our lives are not always about my elder son but they might actually focus on my younger son for a little while. To do that I would have to pay someone to sleep in my house because my house has all the physical modifications that my son is familiar with and he can actually sleep there, and when I come back I will know that he will have slept and so therefore he will not be impossible for us to manage for the next couple of days.

The modifications that our house requires - I mean, we have closed-circuit infra-red TV in his bedroom; the bed is screwed to the floor; the mattress and the sheets are tied to the base of the bed. He wears clothes which he cannot remove because otherwise he would just freeze all night because he can't stay under blankets, would remove all his clothes.  He's incontinent.  We need a personalised sort of service which only flexible funding would allow us to really address his needs.

**MS SCOTT:** You've referred to, I think it's pronounced Kingsdene.

**DIANNE:** Kingsdene Special School, yes.

**MS SCOTT:** That's the one whose board facility was closed, I think, in the last - - -

**DIANNE:** I find it shocking really that there seems to be a policy position taken by the state government that a boarding school for children with severe disabilities is somehow a bad old institution and therefore really is not deserving of public support where that is a sensible model that allows families to be very involved.  The comparison with the bad old institution was it was done on the cheap and families were not involved 30, 40 years ago.  I can see a place for that for a cluster sort of accommodation for people with disabilities; not most people with disability.  Most people with disabilities can enjoy a mainstream lifestyle.  But some have such very high support needs because of their medical requirements or their intellectual limitations that they need really specialised housing which some people may identify that a large group would be the appropriate form of accommodation.

**MR KALISCH:** One thing I was thinking about is in the future.  What are your aspirations for your son.  What can you see - - -

**DIANNE:** My aspirations for both my sons are the same, that they will have a happy safe life.  But the manner in which my eldest son will achieve that is very different from my mainstream younger son and the supports that my eldest son will require are so extensive that my eldest son's future it bleak.  It is desperate.  It is a disgrace in our country.  I have no aspirations because I know that the support that he needs is so grossly beyond what the public purse will provide.  He will just be drugged down to a zombie once I have to renounce him by the time he's about 20.

**MR KALISCH:** That's obviously taking into account what you see as the current service provision?

**DIANNE:** Yes.

**MR KALISCH:** Can you envisage that changing if there was to be a funded disability insurance scheme?

**DIANNE:** I honestly don't have high hopes because the current service is so extremely bad that it is a gigantic change to move from where we currently are to what would be adequate and decent and reasonable and it will cost a terrible amount. People in our community, those requiring constant care because they have very severe disabilities are so marginalised and invisible to mainstream society that I don't imagine there will be political will to fund a decent system of support, so I have no expectations. My hope and dream would be something along the lines of the UK system where people have a right to service of a fundamental and basic level, like the supported accommodation you require because of your severe disabilities should be provided by the public when your family cannot provide it.

But, I mean, I'm giving you - we're talking about the overview. On a daily basis my son is lovely. It's just impossible to find the energy to provide the extreme level of service support that he requires.

**MS SCOTT:** Dianne, because you've given us this material earlier, we've read it, from the many submissions I can recall yours very well. I don't think we need to ask any further questions. Thank you very much for attending.

**MR KALISCH:** Thank you.

**DIANNE:** Thank you.

**MS SCOTT:** I now call forward Melissa Noonan, please. Welcome, Melissa. Could you indicate the organisation you're representing today and would you like to make an opening statement, please.

**MS NOONAN (L4L):** Thank you. My name's Melissa Noonan. I represent Limbs 4 Life Inc and I'm also representing amputees generally in Australia.

**MS SCOTT:** Thank you.

**MS NOONAN (L4L):** We welcome the opportunity to address the Productivity Commission's inquiry into disability care and support and we will be submitting a paper in due course. I thought I would just give you a general overview, I guess. An amputee is an individual who has undergone the surgical removal of a limb or limbs or partial limbs and/or an individual who is living with congenital limb deficiencies. In Australia the main cause for amputation is diabetes. Other causes include, in no particular order, vascular disease, cancer, infection and trauma and children who are born with congenital limb deficiencies.

The Australian Institute of Health and Welfare reported in 2001 that there are approximately 137,000 amputees in Australia but basically it equates to one in 1000 lower extremity leg amputees and/or upper extremity arm amputees. However, I guess we're concerned that with the steady rise of diabetic-related amputations it's estimated that these figures will show an increase in the overall numbers. Further to this in 2008-2009 Diabetes Australia reported that there are over 3500 Australians who have lost limbs to diabetes.

Generally funding for the supply and equipment and manufacture of prosthetic limbs in Australia hasn't increased for about 10 to 15 years. That's to the best of my knowledge and I'll explain why in a moment. Currently I don't believe the funding replicates the increase in diabetic-related amputations and it also doesn't allow for the advancements in technology and the trends in technology. Publicly-funded Australian amputees continue to be fitted with prosthetic equipment which in some cases is equivalent to that of Third World countries. I guess as an example of that, feet that were originally developed back in the 1950s. Obviously this impacts on an individual's ability to contribute to our economy, the society and their communities, not to mention the overall effects on their mental health, long-term physical health and general wellbeing.

In our mind and in representing our stakeholders the ability to measure and define severe and profound disability is difficult. I suppose anyone individual who has their overall mobility or independence impacted upon feels greatly disadvantaged in a number of respects. The aim for most amputees is to regain their independence and to have their ability, where possible - or to have the ability where possible to re-engage with their life, their community and work.

I'd like to share a couple of case studies and stories with you, if I may. The first one is from a girl called Mary who is a 23-year-old woman. She's a triple amputee after contracting meningococcal disease. Mary was confined to hospital for nearly five months while doctors worked to save her life. As Mary states the hospital system spent hundreds of thousands of dollars ensuring her survival. She was left with one arm and no legs. She questions why the health system bothers to put so many resources into keeping her alive when the funding provided for prosthetic limbs is so basic. In order for her to contribute to the economy, gain university skills, be independent and get back into the community and society she has taken a loan in excess of $50,000 to purchase limbs to regain her independence. She believes that she never would have been able to move on with her life with the limbs and the products supplied by government funding.

**MS SCOTT:** Would you be able to provide examples in your submission when you make it - - -

**MS NOONAN (L4L):** Yes.

**MS SCOTT:** - - - about why you consider - you know, demonstrate the 1950s feet versus what would be available in Australia on the market otherwise?

**MS NOONAN (L4L):** Sure, most certainly.

**MS SCOTT:** Okay, thank you, that would be very useful. Please proceed.

**MS NOONAN (L4L):** Thank you. I guess as a comparison, and when we were looking at this we were trying to draw comparisons with similar situations which aren't quite but the national joint replacement registry reports that more than 65 artificial knee and hip replacements were done in 2008 at the average cost of around $23,000 per unit. Public patients can access a hip, knee or shoulder replacement via the Medicare system without any age or financial restrictions, which is a far cry from the funding spent and allocated to amputees. So it's safe to say the financial allocation between the funds of internal and external prosthetics is very different.

I'd like to give you an example of the budget allocation for prosthetic limbs in Queensland - and I'm using Queensland as an example because they were forthcoming with the information. In 2009-2010 was $2.4 million. They currently have 6000 amputees on their books in Queensland with only three and a half thousand what they refer to as active patients. Simply this equates to a cost of $685 per person per year, or approximately $2055 per person over three years. They also state that the cost of supply limb equipment, socket fit and manufactured ranges between 4000 and five and a half thousand for a below-knee amputee. The average cost for an above-knee amputee is close to $7000, leading to, obviously, an ongoing shortfall.  In addition to this these costs relate to the most basic form of equipment. So having said that, a person who wants to and needs to work full-time, be on their feet for a normal working day, could suffer long-term I guess health conditions from wearing basic feet, basic knees with minimal energy return and the impact on their long-term health could be severely compromised.

**MS SCOTT:**   In the funding that is provided, Melissa, are you able to top it up? Like is it case that, I don't know, Queensland will give you a basic leg but if you want a better leg you can chip in and - - -

**MS NOONAN (L4L):**   Absolutely.  It's difficult to - I've got some information on funding a little bit further down the track with respect to the different states, because there is not one model anywhere.  It's kind of an absolute - it's all over the place in some respects.  Yes, you can, but it's difficult to get what - that figure in some states of what you might be provided with so that you can top up the gap, yes.  It's not - I suppose if you were to go - in many cases if you were to go for a replacement limb, unless you're compensable by insurance you don't actually walk in there and someone says, "Okay, here's a pool of 2000.  If you want to spend five you can have this, this" - the information just isn't there.

**MS SCOTT:**   Yes.

**MS NOONAN (L4L):**   Numerous studies suggest that amputees greatly benefit when prescribed with more advanced prosthetic systems such as microprocessor knee units and carbon fibre feet.  These systems also prevent uncontrolled falls which can be reduced through the use of more advanced componentry and in turn lead to fewer injuries; therefore the reduction of long-term health costs.

I wanted to indicate as well that there may also be some financial benefits taking care of older Australians.  While we appreciate that there's boundaries and barriers that need to put in place with regard to the NDIS, in the long term this could be an area of proportionate disadvantage in that amputees over the age of 65 who are taught to walk properly can remain independent in their own homes, stay healthy from the benefits of being able to walk - be less draining on the system with regard to the costs related to hostels, carers and thus require minimal support from the government and service providers; possibly should be considered in including in this group for that reason.

**MS SCOTT:**   Thank you.

**MS NOONAN (L4L):**   I guess in assessing the findings from our consultation, further comments suggest that many individuals would like to be in control of their own funding.  They would like to take care of their own funding and be empowered to make the choices that they need.  Many people state that the funding for amputee health needs to or should be given to the person directly rather than the centre, so that the person can see fit to use it how they so choose.

Another amputee suggests that the current system could be improved by allowing GPs to refer amputees to centres where they believe they would be best cared for and best benefited.  A number of amputees travel interstate because they've had regretful experiences in the state where they currently reside, so they travel interstate and wear the personal cost of that.  If they do travel interstate they cannot also access the funding that they're eligible for.

In addition, assessing the findings from our consultation, further comment suggests that the delay in fitting artificial limbs in Australia continues to increase due to the lack of service providers who actually manufacture artificial limbs.  It's estimated that approximately 65 per cent of qualified prosthetists leave the industry after five short years.  While a number of private providers cover rural and regional communities, often travelling up to five hours to do so, the funding related to provide such a service is very costly.  Amputees also indicate that current waiting times are between three and 12 months within the public system, causing lengthy periods without mobility or independence.  The waiting time for limb fit and manufacture and supply can have a long-term impact on an individual's state of mind; physical ability; ability to return to work, which impacts on their financial status, mental wellbeing and I guess the general chance to contribute to society in a timely and effective manner.

Across Australia there's a disparity in the artificial limb funding scheme. There's a broad number of different models and funding for prosthetic limbs differs in each state of Australia even though the funding is derived from the federal budget. We don't have an equitable system across the country and different rules and different treatment services apply to different amputees in each state and territory. The supply of componentry differs from state to state and often there's no consistency in the supply of certain feet, knees, sockets or liners.  We believe that we need to have a national consistency and the industry needs to work towards benchmarking the services and adopting best practice.  Currently - - -

**MS SCOTT:**   Can I cut you off there, Melissa?

**MS NOONAN (L4L):**   Sure.

**MS SCOTT:**   One model you suggested was that individuals could get control of their own funding.

**MS NOONAN (L4L):**   Yes.

**MS SCOTT:** The other model which you seem to be now advocating is that there is common - sorry, I forgot the phrase but I think you just read out something like "common standards" and so on. So are you proposing an individualised model or are you proposing a national model with a national prosthetic service or something?

**MS NOONAN (L4L):** A national individualised model but one that is, I guess, same - I'm sorry for the confusion - - -

**MS SCOTT:** No, that's fine.

**MS NOONAN (L4L):** - - - but same in each state.

**MS SCOTT:** Okay. So a person would get the money but they wouldn't find that you got a 1950 foot in Queensland and a 2010 foot in Victoria.

**MS NOONAN (L4L):** Correct, yes.

**MS SCOTT:** Okay, got that.

**MS NOONAN (L4L):** Currently there's about 10, if not more, different funding models to support amputees. Obviously there's the WorkCover system. The Department of Veterans' Affairs; the Department of Defence; the motor transport insurance scheme, which differs in each state, including TAC, which is a different model in Victoria; the state government funded Victorian Artificial Limbs Program, which is shortened to VALP, and the government-funded ALS program, the Artificial Limbs Scheme, which is administered by a funding manager in each of the other states. Navigating that system is often confusing.

Just in closing I'd like to say that in general I think amputees need access to better equipment and better general care. Via the aids and equipment program, the waiting time for the installation of ramps and bathroom equipment, wheelchairs, and mobility aids are too lengthy and those delays are slowing down the hospital discharge times. Often the allied health professionals who work in regional communities and rural communities say, because there's often change in those forms and that paperwork as well, for those people to be able to complete them, valuable beds are being compromised by people who are there in them waiting to go home and waiting to return to home, and that to us just doesn't make sense. Thank you.

**MR KALISCH:** Melissa, just about the other schemes outside of the transport and workers comp schemes, the state based schemes, are they funded within the disability programs or in the health system?

**MS NOONAN (L4L):** My understanding is that they come through the Department of Health and Ageing, if that's correct.

**MR KALISCH:** So is it a Commonwealth scheme or are they respective state schemes?

**MS NOONAN (L4L):** No, Commonwealth, which is interesting, as to why they are so different obviously in each state.

**MR KALISCH:** Yes.

**MS NOONAN (L4L):** My understanding is that in Victoria the funding for prosthetic limbs comes from the Commonwealth, is delivered to the Department of Human Services in Victoria and then it's distributed to the 11 accredited public centres and one private centre in Victoria. This differs greatly to any other state in Australia.

**MR KALISCH:** I suppose that means we have probably got to check out what is the funding source, who are the administrators, where are the rules set and those aspects. From what I'm hearing from you, you'd like certainly a national scheme where people have choice and that is responsive to their needs.

**MS NOONAN (L4L):** Absolutely, and I think so that they can make value choices, they can choose models that are going to suit their working lifestyle so that they can contribute to the economy and to society, without needing to go through a debilitating health risk or impacting more on the health system in the future. A lot of studies show that if you're given something that's better to start with, then your ongoing health will obviously be better and you're not going backwards, by trying to walk or have the ability to walk or function.

**MR KALISCH:** One of the things you noted was the lack of information, that people sort of struggle to know what is available, what is the cost, what are the benefits.

**MS NOONAN (L4L):** Correct.

**MR KALISCH:** Are you aware of better information provision in other places that could be a model?

**MS NOONAN (L4L):** Not off the top of my head. but I'm more than happy to investigate that and put it in there. It is difficult to find; and some of the service providers also aren't willing to hand over that information, so to speak.

**MR KALISCH:** I suppose one of the critical dimensions is if you are going to give people greater choice then presumably they have got to have information on which to base that choice.

**MS NOONAN (L4L):** Absolutely.

**MS SCOTT:** Well, this sounds like a mess. I could say other things, but that's probably what can go on the transcript. I don't know where to start. You make a very interesting comparison to hips and knees and so on. I wouldn't mind you exploring in your submission why we seem to be able to organise hip and knee replacements but can't necessarily organise something better than a 1950s foot. Imagine that some governments and departments might have been motivated by the idea that this is a specialist skill required and there might be economies in purchasing 50 feet and then 30 arms and that there might be some sort of benefit associated with a very centralised model. Are you aware that there are economies in buying, say, 50 feet or in fact are everybody's feet different and therefore there wouldn't be many economies associated with having a centralised system?

**MS NOONAN (L4L):** I'm not sure about how the numbers work in that respect, and obviously not everyone is fitted with a foot model like that, there are better things out there. But I think it's frightening to travel around the country and see that people are on very antique kind of systems. Their ability to be able to walk and function would be very difficult. Having said that, multiple purchases, by getting, as you say, 50, I'm not sure if that makes any kind of difference at all.

**MS SCOTT:** Okay. We might explore that. You have left me speechless I think. We look forward to getting your submission. Thank you very much.

**MS NOONAN I(L4L):** Thank you.

**MS SCOTT:** Also, whatever evidence you could provide would be very good. Sorry, I did think of one last question. You made comparisons to the different schemes. Life is a lottery, and it seems to be if you have a disability it's even more of a lottery. In our issues paper we made the comparison between different services available if you're on one side of the border, the Queensland versus one side of the border in New South Wales. If you're in Victoria, could the leg you get be very different if you lost it through diabetes versus lost it through a car accident?

**MS NOONAN (L4L):** Most definitely.

**MS SCOTT:** In which case, I'd be very interested if you could document that. That would be extremely helpful.

**MS NOONAN (L4L):** The compensable patients, through WorkCover, have access to the most advanced technology, which is computerised, and some of it is just quite incredible, compared to the very base model from a public patient through diabetes and vascular disease, et cetera.

**MS SCOTT:** That would be very useful to have. Thank you very much, Melissa, for coming today and for your material. We look forward to getting the submission. Thank you.

**MS NOONAN (L4L):** Thank you.

**MR KALISCH:** Thank you very much.

**MS SCOTT:** On that note we might break for lunch. We're having a longer break than usual, as David has a meeting commitment. On some other days we have rushed people back here. Today we're not going to recommence until 2.20. So 20 past 2 coming back here. Thank you.

(Luncheon adjournment)

**MS SCOTT:** Good afternoon and welcome back to the inquiry. Welcome to the people who have just joined us for the first time. This afternoon we have two people who are providing evidence and I'm pleased to welcome to the table Diana. Diana, could you state your name and for the transcript indicate the organisation you're representing, please.

**MS QIAN (MDAA):** Sure. I'm Diana Qian, spelt Q-i-a-n. I'm representing the Multicultural Disability Advocacy Association of New South Wales.

**MS SCOTT:** Thank you. Would you like to make an opening statement.

**MS QIAN (MDAA):** Yes, and I must apologise for not providing anything in writing beforehand, but I do have a list of issues to bring to your attention and thank you for the opportunity to attend the hearing today. Just briefly about MDAA, about what we do. We're a statewide advocacy organisation. One of our largest teams provides individual advocacy which is to support individual people from a non-English speaking background with disability and their families and carers to advocate for their rights and needs and also participate in the service system and the community of their choice.

MDAA also do systemic advocacy, so we provide input to policy development, advocate for broader changes that will realise the rights of people from NESB with disability. In addition we do industry development which is to work with service providers, particularly the human service sector, so that they are better equipped with the latest thinking and the skills and the tools to provide a culturally-competent service for people from diverse backgrounds. We also have a training arm, we're a registered training organisation. So that, in a nutshell, is what MDAA does, fairly diverse program areas as a small community organisation.

I am aware that this inquiry is not about what's not working with the system - I think we know quite a lot, the system is not working for a lot of people - but to find new ways of improving things. But I have to put on the agenda some of the barriers that people from NESB experience. Your discussion paper is very comprehensive but I'm disappointed to see that the specific disadvantage of people from NESB is not mentioned in the overview and I think if we don't put that on the table, then when we get to designing the system, the needs of people from NESB will just be an afterthought and in my experience of working in the sector for the last 14 years, I constantly appear before inquiries, attend meetings to raise concerns but they never eventuate systemic changes that will bring real outcomes for people from NESB with disability, be it the Commonwealth level or the state level.

So while I'm very excited about this opportunity of creating a vision, if you like, what we'd like to see in the future that will work for people, I'd just like to emphasise that I would like to see the needs of people from NESB considered as a core part of the system, not one line in a report that simply referred to additional disadvantages because that doesn't get us anywhere.

**MS SCOTT:** Understood.

**MS QIAN (MDAA):** I'd just like to highlight some specific issues. The numbers tell us quite a lot about what the problems are at the moment and you have probably heard some of that from my counterparts. Australia is very diverse so you're looking at about 25, 30 per cent of the population from non-English speaking background, first generation and second generation, but the access rate in the disability service system is about 5 per cent average and that hasn't changed over time. What we'd like to see in a new system is that the access rate is compatible to the demographic make-up of the community.

**MS SCOTT:** Yes.

**MS QIAN (MDAA):** There are a whole range of reasons why that access rate is so low and we don't have time to go into it but just very quickly, there is a lack of accessible information and I don't mean in the new system let's have millions of brochures translated into other languages. It's a lot more than that and we often simplify the issues by just saying, "Let's have a brochure." It's the whole spectrum of how information should be communicated in an accessible way, verbal or non-verbal, and also a good understanding of how your target group understand the information that's given. It's a negotiation process basically. So the needs of the community you're communicating with must be at the forefront of any design of information and promotion of the system.

There's a lack of cultural competence in the system as well as at organisational levels, as well as individual worker levels. Throughout the vertical spectrum of the disability sector there's a lack of, first of all, awareness of the need to expand service delivery to be inclusive, as well as the actual competence to design a system that will support the diversity of the population.

MDAA is still in the process of formulating our formal submission and this inquiry is gigantic, it's huge. There are so many things to consider and there is a lot more that MDAA needs to do in our thinking to come up with something concrete. But I'd just like to outline some key features, and they're very preliminary, but they are things that we thing are important in the new system. First of all we'd like to see a system that's about supporting people, not managing disability. One of the, I think, crucial pitfalls in a wider disability system is not working for people at the moment, it's very single dimensional. It focuses on the disability and manages that disability and the person's pretty much peripheral to the service delivery and that doesn't work for people from NESB. Like, I can't separate my disability from myself, my cultural background and who I am as a person. If I go into a service I expect to be treated holistically as a person.

**MS SCOTT:** Diana, can I just make a suggestion and you don't have to take it if you don't want to. But you're going to fast run out of time and I wonder whether you want to go through your key features and then if it turns out that David and I don't understand what you suggest, we would ask you to elaborate on something. I'm just a bit worried that we're going to squeeze our last speaker if I get to you to elaborate on every point as you go through. So, for example, the idea that it would focus on people and support people, I don't think David or I would have any concern about that. That makes eminent sense. How would you feel about just going through your key features and then leave us a little bit of time to discuss things.

**MS QIAN (MDAA):** One of the principles we think should underpin the system is about equity of access and social inclusion. The more funds you invest in an inequitable system, you actually increase the disadvantage that people from NESB experience. There's need to invest in early intervention. If you look at disability support as an investment rather than a cost burden, then investment in early intervention makes sense. Start early, start the first point of diagnosis and you have the likelihood of people being participating members of the community in the future.

There are some issues around how assessment tools are used and they're culturally defined. So for people from NESB from a different cultural background with very different experience about our impairments and our disability, how we assessed need to be able to adapt to the diversity of people.

**MS SCOTT:** Can I just pause there. I don't think I've encountered that statement before in reading submissions and so on. So when you do your submission, could you particularly indicate the problems that arise out of assessment tools.

**MS QIAN (MDAA):** Sure.

**MS SCOTT:** I've heard this in other settings, obviously intelligence tests and so on about cultural things. But given that what's being suggested to us is that we use some sort of functional tool assessment, daily living or decision-making tool, tool about competency to make decisions, I'd be interested in learning about how they can be culturally biased. So can I give that to you as homework.

**MS QIAN (MDAA):** Okay, sure. Happy to take homework. Now, I know a lot of people have been asking for self-directed funding models.

**MS SCOTT:** Yes.

**MS QIAN (MDAA):** Yes, supportive of that, however, a word of caution. It takes a market approach but for people with limited knowledge of what's available or even have limited capacity to ask for something that they don't even know can be possible, so for people from disadvantaged background, that market-driven approach doesn't work.  I came to Australia without any awareness that I can go to school when I stayed at home for two years.  I didn't even know that I can ask to go to school.  That's just an example that people don't know what they don't know.

Interpreting services should be part of infrastructure development, so works in like healthcare - interpreting pool.  Needs investment in workforce development, particularly - you are looking at different systems, asking people to work and think differently.  You're not going to have innovation when everybody does things the same way, so there needs to be investment in workforce, particularly around cultural competence.  The investment in mainstream inclusion and attitudinal change, a lot of the barriers where there is a cost complication for government is about the way our society is structured and social attitudes.  So addressing those barriers are going to, in the long-term, reduce cost.

Invest in promotion in multicultural communities and that will address some of the disadvantage that people from NESB with disability experience.  If information is continually promoted in language-specific ways, media for example.  There's a lot we can learn from social marketing and multicultural promotion.  The importance of maintaining advocacy as a safety and accountability measure.  The availability of services for things that are not the usual.  We're looking at flexible models and if you take a supermarket approach to looking at disability service models it gives the impression that people have choices, but it might not be the reality.  You can't pick something off the shelf when it's not there and that's a concern for people in regional and rural areas, you're not going to have a lot of choice when the market is not there.  That's a concern for people in regional and rural areas.  You're not gong to have a lot of choice when the market is not there.  I sometimes wonder why my wheelchair costs 10 times more than bicycle, although they have two wheels.  Because of the market.

So if we are looking at innovative approaches that are person-centred then you need to factor in the cost to fund something that may not have the demand that drives the market.  It is important to have quarantine and safeguard disability funding for the future, so it isn't dependent on competing needs of other population groups.  With a system that works like a Medicare system or a social security entitlement system you actually have a more guarantee of funds in the long run.

**MS SCOTT:**   That may be your point?

**MS QIAN (MDAA):**   Yes.

**MS SCOTT:**   Yes.  Good.  One of the things you didn't list is funding to services operated within nonEnglish-speaking backgrounds.  I was just conscious that in

Victoria we met with a number of organisations or had evidence from organisations where in order to provide services, including attendant care or advocacy services, they appeal to particular community groups.  Rather than trying to cover all of the nonEnglish-speaking backgrounds, you might have a particular cultural group and language group represented by a particular organisation and then using outreach into the community.  Do you favour that model?  Is it something that you have here in New South Wales?  Would you like to see it as part of a scheme?  Do you have any comment on that?

**MS QIAN (MDAA):**   Yes.  I think a mixed approach would work better.  The mainstream disability support should be able to cater for people regardless of their cultural or linguistic or religious backgrounds.  That's an expectation, that the mainstream has actually diverse and culturally competent support in the majority of services in the sector, and then on top of that you have community-specific services and they provide the choice for people.

So someone like myself, I would like to have the choice to go to a mainstream service where my needs will still be catered for and I'll be respected and not discriminated against as a Chinese person, or I could choose to use a Chinese service.  That choice needs to be there.  Having culturally-specific services shouldn't be a cop-out for mainstream services not including people from diverse backgrounds.

**MS SCOTT:**   Thank you.

**MR KALISCH:**   I was just wondering, in terms of some of the features you talked about, or the principles, what would a good service look like?

**MS QIAN (MDAA):**   A single service or a  service - - -

**MR KALISCH:**   Are you looking at a single service or is it likely that multiple services would need to deliver the type of strategies and services you're talking about here?

**MS QIAN (MDAA):**   I'm thinking more about what the system will look like.  As I said, we need to have solid infrastructure building.  So industry development, a good set of guiding principles, good measures of what outcomes look like.  We fund for outputs at the moment in disability services, not so much outcomes.  If we're going to invest billions of dollars I would actually like to see people's lives improve.  So we're not good at measuring qualitative life outcomes in the system at the moment.  There needs to be an appeal system about decisions, there needs to be consistency and there needs to be the capacity of the system to actually be flexible and improve.  So that's what the system will look like.

Now, if you come down to the subsections of that system, then there needs to be a range of services that support people on key life stages. So you will have early intervention services, you will have services for school leavers. They are key life stages and that's where it's worth investing. If school leavers have appropriate transitional support to tertiary education or post-school programs they have much more likelihood of obtaining meaningful employment and also participating meaningfully in the community.

But for people from NESB with disability that transitional support is not there, so most people retreat back to the family home and probably resurface 20 years later in a crisis situation, and that's a high cost end of disability support in crisis accommodation, where people have limited living skills. There should be programs, as I said, to address barriers. Disability is about how impairment interacts with our environment, the context that we're in, so if you improve that built environment as well as social environment you're actually going to reduce the level of disability that people experience.

Entitlement, eligibility, I think that came up quite a lot. You heard a bit about that. I can't emphasise enough avoiding, you know, focusing on how profound the level of impairment, but also to have a balanced system that looks at people as more - you know, more with disability. My wheelchair costs taxpayers $3000 but I paid $10,000 in tax. So I think that that's a worthwhile investment. Without my wheelchair I'd be a high support need, and with my wheelchair I wouldn't feature in the ABS data. At the service level there needs to be good governance and policies and a diverse workforce that can actually respond to the diverse needs of whichever target group that they have in their community.

**MS SCOTT:** Thank you.

**MR KALISCH:** Thank you.

**MS SCOTT:** Thank you very much, Diana, for coming along. We look forward to getting your submission. Thank you for making the time today.

**MS QIAN (MDAA):** Thank you.

**MS SCOTT:** We now have our last witness here in Sydney, after two and a half days. Sue O'Reilly, please. Sue, for the record, could you indicate whether you're representing yourself, your family or an organisation, please.

**MS O'REILLY (FC):** Probably all. My name is Sue O'Reilly. I am the founder of a small disability charity called Fighting Chance, which I'm representing today. I am also co-founder of the Australians Mad as Hell campaign, for which I am not really particularly speaking today. I am also the mother of a 20-year-old son with quite severe cerebral palsy. I apologise, you have a very early draft of my submission. I just sent the final in at 4 o'clock yesterday afternoon.

I have been a journalist for 35 years, so I have done an awful lot of writing, but this was far and away the hardest thing I have ever written in my life, I think because it matters so much to me personally and to so many others. This is literally a matter of life and death, certainly life and living death. I did about 400 drafts. But the one that I finally sent in yesterday really does encapsulate most succinctly what I wanted to say, and I apologise that you haven't seen it, because there were issues raised in it that are not in the earlier draft you've got. But hopefully you'll get a chance to read my final.

It's very hard to know where to start. It's very hard to know where to stop. But I would like to focus on the solutions rather than the problems, which I'm quite sure you don't need to hear about any more from me. I would like to say though that the current system is absolutely beyond repair. It's not a matter now of any more bandaids, any more incremental changes, any more layers of bureaucracy on to the existing system. The current system has to be completely scrapped and we have to go right back to the drawing board and we have to start all over again, designing a really coherent, intelligent, well-coordinated system, which is an extremely daunting prospect.

It's going to be like doing major roadworks on the Pacific Highway in the middle of rush hour. So it's extremely daunting and difficult, but it's also an exhilarating challenge as well. It's absolutely wonderful that this inquiry is happening, and it couldn't be with a better body so to have the intelligence and the skills to be able to recommend what needs to be done - nobody underestimates how daunting the challenge is for you - and then for the politicians to receive what you recommend.

Many people are extremely impatient, but I'm not one of those. I personally would rather see this done properly, however long it takes, as long as we can be assured people are getting on with it and are addressing it constructively, not just going around and around in circles, further delaying. I could see this easily taking probably 10 years to fully implement, because you're obviously going to be dealing with all of the people currently in the system as well as the new ones coming in.

But it seems to be absolutely essential that we abolish what we currently have, which is nine federal state and territory disability bureaucracies, as I go into in my submission, all wasting vast amounts of very scarce resources; that we have one centralised national body, similar to the Health Insurance Commission which administers Medicare, and that this be the entry point for everybody coming into the system, either people currently in the system now or newcomers; that this streamlined national, unified body has regional outreach offices all around Australia so people can go to a local centre, they don't all have to troop to Canberra obviously.

From the time a disability is diagnosed that's where you go, that's the starting point, you go there and you have a case manager who opens an electronic file for you and all that information is then in some spot and you don't have to go through over and over and over and over again every time you apply for a service, that information is centralised and follows you for the rest of your life, it instantly provides a sort of one-stop shop that everybody has talked about for years and no-one has ever been able to implement.

You have a system there where your needs are assessed, which is possible to do on the basis of the diagnosis, even if it's a preliminary thing that will change over time, it can be entirely flexible.  But I see it operating as something like the court system now, where if you go to court and you win a large settlement because you have a very severely disabled child the court is able to assess on the basis of known actuarial charts and facts what the ballpark lifetime support costs are going to be. Courts then award a settlement, and in cases of extremely severely disabled people it's millions of dollars.

I think it's possible that each person on the basis of their disability can have a sort of nominal sum that is basically set aside in trust, held by this national body, to be released as and when the services and support needs on the agreed official list as those needs arise and then that funding is released.  Individualised self-directed funding is an essential part of that, as so many people have said.  This sort of system allows for that.  Alternatively, if people don't want to make the decisions, can't make the decisions, then there's the flexibility to make alternative arrangements.

There's also the flexibility to change over the life course as people's needs change, their levels of information and awareness.  It's an incredibly flexible system. It meets many of the needs the previous speaker was talking about, where if you have needs because you're from a nonEnglish-speaking background that can be taken into account.  So it's a very individualised system, but it's one national streamlined system.  I know there have been concerns raised with you that this would be some sort of monolithic, all-powerful bully.  I completely disagree with that.

The way you overcome that is you do what so many other countries do, what they do in the UK I certainly know, and that is you have a legal entitlement to service. So you move disability services out of the political and far more into the legal administrative system so that, as I explained in my submission, you take it out of that day-to-day rough-and-tumble political process, from where it has to be taken out, then people's entitlements to services are protected by law and this centralised national body, this disability insurance commission, or whatever it's called, then has to apply that law, you have administrative tribunals, appeals mechanisms and so on, as happens in a number of other cases.

The people who argue against a sort of monolithic national body seem to me to be completely missing the point that when there's billions of dollars of taxpayers' money being spent, as there has to be and will be, of course you have to have some sort of body that administers that, and a national body established by legislation that is answerable to parliament seems to me to be the most accountable way to proceed with that. There's I think these fears that people have raised about insurance instantly means sort of big commercial companies making decisions. To me, that's just a furphy.

Again I don't need to talk about early intervention therapy, that has been stressed over and over again to you. But the point I would like to make is I think it's incredibly important in this wonderful, new national streamlined system, if we are to have it, that we move away from the very narrow medical model of disability, which I also go into in more detail in my submission. I think that has really been very toxic. It's particularly powerful in Australia because of the rigidities and dysfunctionality of the current system.

To me, we have to move much more to an educational model of disability that looks upon disability as a developmental challenge, not as an incurable medical condition. When you start thinking about it in educational developmental terms you move from the passive verb "treat" to the active verb "learn" and you just instantly have all sorts of practical flow-on benefits from that, in that you achieve all sorts of things that the rhetoric talks about: valuing people with disabilities, valuing their potential, valuing their potential contribution to society. They cease to be seen as hopeless and incurable medical cases and actually people who can learn and we all can learn; everyone can learn until the day they die. Then you instantly, by its nature, start to change attitudes towards and treatments of people with disabilities.

I hope that the commission is going to have an opportunity to speak to Dr Norman Doidge - I did send details through about his tour to Australia. His book, the Brain That Changes Itself, every single page, the verb that recurs over and over and over again is "learn". All the cutting edge medical science and research now is beginning to understand finally and accept that the brain has far more potential for repair and people have far more capacity than the medical profession has so far acknowledged. So it would be, I think, detrimental if we did put more emphasis on early intervention and therapy but continued to do within this fairly narrow, old-fashioned, rigid medical model, that we looked upon early intervention far more as an educational process.

I also wanted to talk to you - and I don't know, this is probably jumping the gun - about how you actually sell to the Australian people a transformational, new disability system and this is probably beyond the actual Productivity Commission report.  But to the extent that this may possibly concern you, how can this actually be sold politically?  Because that is the ultimate question.  First of all it's essential that there be visionary reformist political leadership of the type we no longer see much of any more.  Hopefully you will make a compelling enough case that it will elicit that. But I think it's also possible to appeal to Australians on two levels:  first, the deepest myths in a literary sense of how Australians think about themselves, the concept of mateship, the concept of reaching out to help those less fortunate, the concept of helping the underdog.  I believe there is an appeal that can be made to Australians there, that's why all Australians need to support this.

But, secondly, just self-interest.  It's entirely possible to appeal to people's sense of self-interest by pointing out, "Don't support this out of sympathy for the people who are currently disabled and need help, support this because one day this might be you.  This actually can happen to you.  You are not invulnerable.  No-one is invulnerable.  This can happen to anyone.  To have that safety net of coverage is a very beneficial thing for any society to have.  You never know, you might need it."

I believe it's possible to sell this to the wider Australian community and I would like to see, if and when we ever get to that point, that actually people with disabilities and families, parents, carers be much more directly involved in the process, that this whole process sees the benefit of a major move away from just the paternalistic thing that we're constantly exposed to now of other people making decisions for us and deciding what's in our best interests; very well intentioned, but the road to hell is paved with good intentions.  As I say in my submission, hell is where far too many of us are living right now.

**MS SCOTT:**   Okay.

**MR KALISCH:**   Sue, thank you for that and I really appreciate the way you've provided us with that sort of structured vision and substance around what you see the system might look like.  I suppose I just wanted to touch on one point at this stage around the legal entitlement to services and I suppose just reflect on the nature of human services in most countries provides an expectation of service, provides a sense of eligibility and entitlement.  But still within those systems there is often rationing, there is often waiting and I would hope that any transformational change would certainly be far superior to what we've got now.  But do you see that there could still be some rationing in terms of a funding arrangement?

**MS O'REILLY (FC):** Yes, there will always have to be rationing. Resources are finite and there are always going to have to be cut-offs and they're going to be arbitrary points. My family and I went into disability exile from Australia in 1995. We moved to the UK as I explain more in my submission. We had the benefit of living in the UK for 12 years under a system where entitlement to basic services and supports are enshrined in law. There are all sorts of incentives - once you actually make it that people are entitled to services, that it is no longer an option for a government agency to say, "Yes, you're eligible for a toilet chair or wheelchair," or whatever, "but, sorry, tough luck, funding ran out three months ago. Apply next year or maybe the year after" - once that is no longer an option, there are all sorts of incentives for the service-provision system to operate far more efficiently. So you just get much more service for the available funding.

It's not perfect in the UK, there are still dissatisfaction and complaints but the way in which basic services, equipment, respite, school support, therapy - because it's enshrined in law, the process is you go through an assessment process where your needs are assessed, that is then agreed upon between you and the assessor and once it's agreed upon, then those needs are met, compared to Australia, with the most extraordinary efficiency. As I think I spelt out, my son needed a wheelchair, we went to the local wheelchair service, the wheelchair was sorted within about three weeks because that's actually efficient and a cost-effective way to do it. To stuff people around for three years waiting for a wheelchair, apart from anything else, it's really, really wasteful. There are so many resources just wasted in not providing the service. You can actually save a lot of money by actually just doing it efficiently.

Again, an occupational therapist came to our house. Again, extraordinary to an Australian. Rang me up and said, "Can I come to you?" came, said, "You need this, this, this," put in an order, three weeks later it turned up. All the incentives are once you have legal entitlement that that's how they operate. The benefits that brings in terms of just making the system actually be a support system. If you're going to do anything at all, do it properly. What's the point of having a support system that actually makes your life harder and tougher and makes the suffering even worse because at the moment in Australia things are dangled in front of you and there's all these web sites about, "We do this and we do that and we do something, here's the number to apply," and you go, "Great," and you ring it up and you apply and they say, "What makes you think we'd have anything," and you go, "What's the point of the web site? What's the point of saying - what's the point of raising these expectations. Are you sadists? What do you see as the point of this?"

Yes, so clearly there is always rationing and there's always cut-off points but, as I tried to convey, I just think the economic case is unassailable, that's there's all sorts of good incentives if you actually do provide a legal entitlement to service.

**MR KALISCH:** Did you have any exposure to individualised funding packages?

**MS O'REILLY (FC):** Yes, we did and again absolutely excellent. The way it worked was somebody came around, a social worker or someone, had a discussion with me about what I needed, she said, "Would 25 hours a week" - of somebody, sort of respite, in-home help thing - "be okay?" and I said, "Yes, that would be wonderful. Thank you very much." They then have a set rate of GBP8 an hour multiplied by 25, that amount was then deposited in a bank account. They had some sort of intermediary service to do all the paperwork and the taxation stuff and all that, so we didn't have to worry about all that sort of fiddly accounting paperwork and everything. The counting process, in terms of me, was very simple and straightforward, I just had to send in a bit of paper once a month. I then had that, whatever eight by 25 is, in my bank account, they then helped me put me an ad in the local paper, I was then able to interview.

I was able to choose. I was able to select somebody I was happy with, that I felt would be good with my son. So a wonderful sense of control and choice. That person was wonderful, and we had 25 hours a week of in-home support. If that had been provided by a government agency or department the cost would have been massively higher. To give you an example, there's something called Commonwealth Emergency Respite Service, or something. My son wakes repeatedly through the night, I get to the point from time to time where I can't go on, and I rang this emergency service at one point, I said, "This is an emergency," and they went, Oh, ah, all right," sent somebody.

They got on to an agency who sent someone. I then got a piece of paper saying, "This emergency respite" thing, you know, "wonderfully provided to you by the Commonwealth cost $897.40. Would you be willing to make a contribution toward this, voluntary?" I got back on to them and said, "Would you be willing to actually think about how on earth anyone can justify that being $897.40 of taxpayer's money. That is absurd. You could give me $160 directly and I could employ someone," instead of the Egyptian person who turned up from the agency who couldn't even speak English, who couldn't understand my son, who my son couldn't understand, and who ended up having to wake me five times in the night to tell him what my son was saying. So the inefficiencies are just boundless.

**MS SCOTT:** That's a very useful example. Did you include that in your submission?

**MS O'REILLY (FC):** No, I didn't.

**MR KALISCH:** Would you like to?

**MS O'REILLY (FC):** I'd like to try and find the bit of paper, yes.

**MS SCOTT:** It would be quite useful actually. We heard this morning, Sue, people from one organisation provide an intermediary service where their overheads are 7 per cent. We have heard earlier evidence where overheads were 20 per cent, 30 per cent and so on. So with the message about individualised packages in the hands of the people I think we have got quite good evidence. Can I go to something else? We have got to be conscious of time. You have said in your earlier submission you want to sweep away the multiple levels of bureaucracy, local, state and federal.

There are some - small maybe - elements of existing arrangements that do seem to work and people have pointed out bits and pieces that work. Is it a case, in your view, that we should try and rescue those? Should we sweep it all before us? Are the people the problem or the system? For example, you'll need a workforce. In some states it's the states that employ some of the workers. Would you be happy to see the retention of state-provided services, provided you had the choice to use them or not? Do you want to do it in stages? Is there anything in the existing system that you think should be retained?

**MS O'REILLY (FC):** I'm sure there must be. I can't think of any off the top of my head. I would think it would be entirely possible within this new national structure, with its sort of regional and local outreaches to retain what works. I also mentioned giving consumers the power to vote with their feet. There's a small agency, for instance, we access. It provides recreational support and it's brilliant, it's small and it's young and it's very responsive. I would absolutely happily continue to choose for them to be the service provider for my son's recreational needs. You would I think sort of almost automatically retain what works, because consumers would continue to select that. But there's also a huge incentive then on the things that aren't working very well that they start working or they go out of business.

In terms of the states being providers, I think ideally you'd get the states out of it altogether. For instance, thinking about Medicare, the states don't have any involvement, apart from running hospitals, which is now being transferred much more to the Commonwealth. The trouble with state based things is you just start to get that fragmentation, you start to get what I think Fiona talked to you about, you get this crazy thing where you get to the border of one state and another and everything stops, which I would have thought was against the Australian Constitution myself, but I'm not an expert on that.

**MS SCOTT:** It's okay for milk to travel across the border but not wheelchairs, so there we go. Sue, thank you very much for your material.

**MS O'REILLY (FC):** If I could make one final point that just came up earlier, in terms of equipment. I don't understand why the vast majority of disability equipment is imported from overseas, a lot of it from America, and as a result costs an exorbitant amount of money by the time it finally gets here. People I know have sourced equipment overseas, it has been a fraction of the cost of what it is by the time it gets to Australia and then goes to all the different middle men.

I don't really understand why we can't have much more of a local based industry manufacturing and developing disability equipment. It would mean job creation and it would, I would have thought, economically be a lot more efficient and cost-effective if we had local production of electric wheelchairs, say, car seats, all sort of things I don't understand why currently we need to import from America, frankly.

**MS SCOTT:** Thank you very much.

**MR KALISCH:** Thank you.

**MS O'REILLY (FC):** Thank you.

**MS SCOTT:** I understand you want to say something.

**MR MacLENNAN:** Yes.

**MS SCOTT:** We'll give this gentleman a go. Is there anyone else who is going to say they want to have a go as well? No? We will give you five minutes. I will just ask you to give your name.

**MR MacLENNAN:** My name is Stewart MacLennan. I am a person with a disability. I have multiple sclerosis. I'm very grateful for the opportunity to briefly address you this afternoon. I want to talk very briefly about something that I feel is largely being forgotten about in the area of our battle for how we make life more equitable for people with disabilities. I have just returned from being overseas, in the UK, where I saw a system which I think has got relevance to Australia. I have written a submission, but I felt I'd just come along and just very briefly talk about a couple of elements of that.

The Disability Discrimination Act largely has the agenda of trying to make life more equitable and more fair for people with disabilities. But the way in which the GST is handled in the system provides an additional barrier for people with disabilities. If I buy this wheelchair for $17,000, originally an Australian design but now made in America, I do not pay GST on this chair. But I'm just about to get new batteries in this chair, which will cost me $800, and I will get new tyres on the chair at $50 each. Because they are parts of the chair, not the chair, I have to pay GST on them.

The way in which the legislation acts is like this, it says that because those parts, ie the batteries, were not specifically designed for a disability and are commonly available therefore GST has to be charged. Are they assuming that I'm going to put those batteries in my golf buggy or that I'm going to put those tyres on my barrow? No, obviously not, but that's the way the rules are. Now, in the UK what happens is that a person fills in a form when they want to get something - for example, I bought a new cushion for my wheelchair over there, the cushion here was $900, the cushion that I bought in the UK was $300 equivalent, which backs up what was just said - and because I just had to fill in the form I didn't have to pay the 20 per cent VAT there.

I believe what we need to do is we need to look at a system whereby even if something is commonly available or not specifically designed for a person with a disability - but through some proper process so that people can't abuse the system - that things can be GST-free, because there is a 10 per cent penalty on disability. As we move to a situation where more and more people need to have their homes modified we need to use the same approach for modifications on homes. It costs about $30,000 to have one's bathroom changed, to have a ramp put in to get in the door, to have the kitchen modified, but one pays GST on the goods and the services to do that.

If I had my car modified, that is GST-free. But the same rules do not apply for home modifications. So that is a great opportunity to be looked at. I have written a 10-page submission on this, but I very, very much value the opportunity to explain it in brief form, because I'm about to have new batteries put in this chair tomorrow, I'll be paying GST on them.

**MS SCOTT:** Thank you very much, Stewart.

**MR MacLENNAN:** Thank you.

**MS SCOTT:** Thank you for being so brief. We now adjourn our hearings. Thank you for all attending and to those that have sat through other people's testimony. We do welcome submissions and we do read them. I adjourn, and we will recommence hearings in Perth tomorrow. Thank you.

**MR KALISCH:** Thank you.

AT 3.23 PM THE INQUIRY WAS ADJOURNED UNTIL
THURSDAY, 22 JULY 2010