S&C

SPARK AND CANNON

Telephone:

Adelaide	(08) 8110 8999
Hobart	(03) 6220 3000
Melbourne	(03) 9248 5678
Perth	(08) 6210 9999
Sydney	(02) 9217 0999

TRANSCRIPT OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT CANBERRA ON MONDAY, 12 JULY 2010, AT 9.06 AM

Continued from 16/6/10 at Adelaide

INDEX

MS SCOTT: Good morning. Welcome to the public hearings for the Productivity Commission inquiry into disability care and support. I thank you for attending today. My name is Patricia Scott and I'm the presiding commissioner of this inquiry. My fellow commissioners are David Kalisch and John Walsh, and John will be joining us by Skype today. The inquiry started in April, with a reference from the treasurer. The Australian government has asked the Productivity Commission to examine the feasibility, costs and benefits of a national disability scheme that will provide essentially long-term care and support, manage the costs of long-term care, replace the existing funding for those people covered by the scheme, take account of the desired and potential outcomes of each person over a lifetime, with a focus on early intervention; provide a range of coordinated support options, including accommodation, aids and appliances, respite, transport, day programs and community participation, assist people with disabilities to make a decision about their support, provide for people to participate in education, training and employment where possible.

The Australian government has asked the commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. We've already talked to a range of organisations and individuals with interest in the issues and submissions have been coming in to the inquiry following the release of an issues paper in May.

We are grateful for the submissions already received and submissions can be downloaded from our web site at www.pc.gov.au. While we'd like to get submissions as early as possible, in view of concerns raised by some participants, the commission has extended the due date for initial submissions to Monday, 16 August 2010. The commission also welcomes third or fourth submissions. Feel free to put in as many as you wish. These submissions may include additional points you wish to make, comments on other submissions and the results of community consultations. The purpose of these hearings is to provide an opportunity for interested parties to discuss their submissions and their views on the public record. It is also an opportunity for the commissioners to ask questions of those presenting material.

Further hearings will be held in Brisbane, Perth and Sydney and we've already held hearings in Hobart, Melbourne and Adelaide. We will be working towards completing a draft report in February next year for public comment and then we will invite participation at another round of hearings after interested parties have had their time to read and consider the report.

We would like to conduct all our hearings in a reasonably informal manner, but I do remind participants that a full transcript is being taken and for this reason, comments from the floor will not be taken. Around lunchtime today, I will provide an opportunity for anyone who wishes to to make a brief presentation or comment, even if you haven't said that you're going to provide evidence today. Participants are not required to take an oath but are required under the Productivity Commission Act to be truthful in their remarks. Participants are welcome to comment on issues raised in other submissions. Certainly in Melbourne we had a number of people presenting to us who commented either favourably or not on earlier evidence they had heard. You are certainly free to come and go this morning as you wish. Transcripts will be made available from the commission's web site following the hearings. This is a good time, if you haven't already done so, to turn your mobile phone off or to silent because we wouldn't want you to interrupt other participants' testimony.

Are there any media in the small audience today? No, okay, thank you. To comply with the requirements of the Commonwealth occupational health and safety legislation, you're advised that in the unlikely event of an emergency requiring evacuation of this building, please follow the instructions of the PC staff, and we'll identify ourselves to you if that is required. So without further ado, I would like to invite Nicole Lawder to come forward and present her evidence to the commission.

MS LAWDER (DFA): Good morning.

MS SCOTT: Good morning. Thank you for coming along today. For the record, could you state your name and your organisation and would you like to make an opening statement?

MS LAWDER (DFA): Yes, thank you. Nicole Lawder, CEO of the Deafness Forum of Australia. Thanks for the opportunity to speak today. I'd like to start with just a brief definition of the terms that we use to describe deafness. When I use the term "deaf", I usually mean like a capital D "Deaf" which refers to people who use Auslan as their preferred mode of communication which is Australian Sign Language. Members of the deaf community share a common language and culture which they feel makes them a minority cultural group rather than a disability group.

People who are hearing impaired or with a hearing loss or hard of hearing tend to be those who use oral language. They may also use hearing aids or cochlear implants. Whether you're a member of the deaf community or someone with a hearing impairment doesn't necessarily relate to the extent of your hearing loss. If you use Auslan, it doesn't necessarily mean that you have a severe or profound hearing loss, it's a communication choice by the person involved.

Deafness Forum welcomes the possibility of a long-term care and support scheme to provide the assistance necessary to Australians who have some form of hearing loss to enable them to participate fully and productively in society. We believe that the UN Convention on the Rights of People with Disabilities should play a central part and underpin the design of such a scheme. The UN Convention on the

Rights of People with Disabilities includes obligations specific to particular aspects of inclusion and participation, including personal mobility, including facilitating affordable transport and affordable access to aids, devices, assisted technologies and forms of live assistance.

Affordability and availability of services and accessibility of goods, services and premises are of a key concern to people who are deaf, deaf blind, have a hearing impairment or a chronic disorder of the ear. Sensory impairment is specifically mentioned in the United Nations Convention on the Rights of People with Disability and at Deafness Forum we're very concerned to ensure that this group may be included within a long-term care and support scheme because without adequate support, people with hearing loss are excluded from many aspects of society.

Historically and still today, hearing loss is the unseen and often unrecognised disability because the impairment doesn't affect the person's mobility, impact on their ability to care for themselves or even is visible to other people. However, these people are affected by being excluded from participating in society due to the financial burden of their disability, the limitations placed on a person with hearing loss because of the lack of access and inclusion.

Helen Keller, who was a well-known deaf-blind advocate, once said that blindness excludes you from things, whereas deafness separates you from people, so it's social relationships that are affected mostly by deafness. On the other hand, there are many, many things that can be done to facilitate that inclusion, whether it's support services or goods.

According to an Access Economics report from 2006, the productivity loss of hearing impairment is $11.75 billion per annum. Furthermore, there is the impact of taxation revenue for the government, lower workforce participation, absenteeism and even premature death mean that the people affected are contributing less income tax revenue. Lower income revenues among people with hearing loss mean lower capacity to consume goods and services than people with "normal" hearing - and I say "normal" with inverted quotes. Reduced consumption of goods and services means reduced consumption tax contributions. Currently, the Australian government spends on average $62 per person on hearing impairment in Australia per annum. The economic cost or impact to Australian society per annum is $3314, so the impact to society is far, far greater than the amount the government spends currently. Those figures are from the Access Economics report. I did send you some other points last week, so I'll finish my opening statement there and happy to take questions.

MS SCOTT: Thank you very much. Nicole, in the points that you provided us earlier, you made mention of the fact that deaf children finish high school with literacy levels of a year 8 student on average. Could you talk a bit more about that, about why their education is set back so significantly, and maybe talk about the educational experience of children.

MS LAWDER (DFA): For children with hearing loss, much of their time at school is often spent trying to listen rather than learn. That may be because of inadequate supports that are provided in the classroom. For a child that uses Auslan in the classroom, there can be up to four people required to support them in the classroom, maybe two interpreters - because for OH and S reasons, interpreters tend to work about 50 to 60 minutes at a time before they need a break - there may be a notetaker, and again a notetaker may need to alternate. When someone points it out to you, it's quite apparent but if you haven't thought about it, you mightn't realise for a visual language like Auslan, the student must watch the interpreter intently at all times. They can't look away to write notes. As soon as they look away, they've lost what else is going on in the classroom. It also means that that child won't be engaging much at all with the teacher because they're not even looking at the teacher, they're looking at the interpreter, and they don't engage with others in the classroom. They don't hear when other children ask questions, for example, and they don't know to look around the classroom because their focus is on the interpreter.

For children for whom Auslan is their first language, English is of course their second language, so they face the same barriers as any other child that has English as a second language. Depending on their family circumstances, they may use only Auslan at home, or they may be the only deaf child in a hearing family, so they don't have support for their own language at home unless the rest of their family also learn Auslan, so they're excluded from many activities, even in their own home. Their parents may struggle to help them with their homework, for example, because they're lacking in the same language as their child. Reading is a real struggle for children and even just the workforce issue such as the availability of qualified interpreters and notetakers, especially outside of the major metropolitan areas, is a real concern. There's an undersupply of interpreters currently and as more families stand up for their rights to demand interpreters, that supply is becoming more and more strained.

For children who are brought up oral and who may rely on hearing aids or cochlear implants, it can often depend on the goodwill, if you like, of their teacher, who may have to wear a microphone. There's been examples of teachers who refuse to wear microphones. As soon as you go outside of a normal classroom environment, for example, to sport or cooking and those other type different-type classrooms, the environment for the child changes dramatically.

Many people don't necessarily understand that when you have a hearing loss, it tends to occur at certain frequencies. It's not just a matter of speaking louder so someone can hear you. You lose parts of words, so lip-reading might assist some people but that's only about 30 per cent of words, because many words sound the same or look the same from lip patterns. One example from my own staff was not exactly a swear word but an example, one of my staff did a certificate for me and he's very profoundly hearing impaired and wears one cochlear implant and one hearing aid. He did two certificates and asked me which one I liked best and I pointed to one and said, "That one's crap." So a little bit later, he came to me with 10 of the same and I said, "What are you doing?" He said, "I thought you said that one's great," because "great" and "crap" have the same lip patterns, so that's just one very simple example of the misunderstandings that can occur in the classroom that's enormously exacerbated.

It's really, really tiring watching someone all day, trying to focus on your hearing, because even with a hearing aid or a cochlear implant, your hearing is still not the same as it appears. They're fantastic inventions but they do not fully compensate for the loss of your hearing. So that child is concentrating on listening all day long, they're looking at the teacher really intently and they really start to lose their concentration and their ability to follow and to learn, and I think that's the real difficulty.

MS SCOTT: Nicole, what proportion of children - if you know this, and if you don't, we could have discussions with you later about how we could obtain this - but what proportion of children born with a hearing impediment that's severe would ultimately at some stage then go on to have a cochlear implant and how many would be reliant on Auslan entirely and what proportion may have some small benefit from a hearing aid?

MS LAWDER (DFA): Generally speaking, about 25 per cent of people with a hearing loss get a hearing aid and that's across all ages. For cochlear implants, it depends very much on your type of deafness. It's not something that every deaf person will benefit from. Even then, some parents may choose not to implant their child for a number of different reasons. I'm not positive of the exact number, but I believe it's around 75 per cent of deaf children will go ahead with a cochlear implant. Nine out of 10 deaf babies are born to hearing parents which is why many parents feel that an oral approach may be best. They're not aware of and familiar with deaf culture and the use of Auslan.

MS SCOTT: Could you talk about the assistance currently provided by the Australian government or by other governments for access to hearing aids in the population?

MS LAWDER (DFA): Currently there's a really good program run by the Australian government through Australian Hearing, under the Department of Human Services, which provides assistance for children under the age of 21 and people over the age of 65. There are some minor variations; for example, indigenous people can get access at about age 50. But generally speaking, for the working age group there's no government assistance. So for a child, they can get their speech pathology, hearing aids, cochlear implants et cetera provided through Australian Hearing, but there may be a number of other costs that the family will bear, which might include special equipment in their home to enable the child to hear the doorbell or watch TV, for example. Some parents choose to purchase equipment for school because the equipment provided by the school may not be of the standard that family feels appropriate for their child. There can be additional costs; for example, if the family chooses to learn Auslan, they will pay for the costs of that language training themselves as well.

MS SCOTT: The reason why I'm asking is because in your points that you provided earlier, Nicole, you're saying that it's possible for families to find that they're out of pocket to the tune of $15,000 to help their children acquire language. Is any of that expenditure able to be deducted by tax or claimed on Medicare or any other form of assistance?

MS LAWDER (DFA):   No, that's early intervention for children which tends to be from sort of ages nought to four before they enter the formal education system. So it's a private provider who usually provides that early intervention. Some of those providers might get some government funding but the parents are still charged 12 to 15 thousand dollars per year for several sessions a week to acquire language. You can't wait for your child to start school before learning their first language. The optimal window for learning language is in the nought to two years of age, and if you miss out in the first two years of life, you're going to be behind your peers all the way through.

MS SCOTT: Okay, thank you for that. John, thank you for joining us. I might just see if David has some questions.

MR KALISCH: I just have a couple, Nicole, about I suppose the nature of the service requirements and the cost of the requirements. You've just talked about the early intervention services and I'm just wondering about those also, say, of workforce age, what requirements they would have that aren't covered by current government assistance and would you envisage that assistance for the working age would be covered by a new national scheme?

MS LAWDER (DFA):   Yes. To enable greater productivity amongst people who are deaf and hearing impaired, assistance in the workplace is very important. People with all forms of deafness tend to be unemployed, under-employed and retire early at greater rates than their hearing counterparts. Currently there's a government assistance scheme for the use of Auslan in the workplace. However, that's capped at $6000 per year currently, so it depends very much on your workplace as to your requirements. But you can imagine if you had a team meeting for one hour once a week, two performance reviews a year, two two-day training courses a year, that $6000 is gone and you don't have the opportunity for further assistance for meetings with clients and other ad hoc meetings. So that's just an average-type employee.

If you were in a position like mine, where you're going out to lots of different meetings and you may have to take your own interpreter with you, at quite extensive cost - again remembering the OH and S requirements for the use of the interpreters - at training courses and conferences, you will tend to have three interpreters working in the team, so that's quite an expensive undertaking. $6000 is a welcome contribution but I know from my own deaf staff that it just doesn't go very far at all. There's no comparable assistance for people with hearing impairment who may benefit in that same staff meeting and the same conference or training course or performance review. There's no allowance for real-time captioning or notetaking, for example. Currently the Employment Assistance Fund just say, "That's not included. If you're deaf, we have Auslan interpreters." But if you went deaf tomorrow, you probably wouldn't use Auslan because you don't know anyone else who uses Auslan. You would be trying to continue in your hearing world and get supports to help you in the workplace to continue the way that you have throughout your career, and that's really what's currently missing.

Also, through workplace modification scheme, you can get assistance for special telecommunications equipment et cetera but again, both through my professional experience and also personally at my work, it's capped and it's at the discretion of the assessors, most of whom have never assessed a deaf or hearing-impaired person before and they say, "You want an electronic whiteboard?" because for me, I can then explain things to my staff and print it out, because they have to watch me the whole time and then they have to write notes and I have to stop talking while they're writing notes. So every meeting takes twice as long in our workplace. I ask for an electronic whiteboard and they go, "That's very expensive, we'll just give you a normal whiteboard," which isn't particularly helpful. It doesn't help with that notetaking at all, from an assessor who'd admitted they had never assessed a hearing-impaired person before. So it's not what the deaf or hearing-impaired person knows they need to support themselves in the workplace.

MR KALISCH: Can I follow up that question where we refer to the workforce: is that a major constraint in terms of provision of services?

MS LAWDER (DFA): Yes. I think many people keep their hearing loss hidden because they're afraid how it may impact, and then choose to take an early retirement when it becomes too much for them in the workplace. They start to feel excluded from everyday events. They might be getting a cup of tea in the staffroom and they can't sort of follow what's going on.

MR KALISCH: Sorry, my question might not have been particularly clear. I was actually asking about the workforce providing services to deaf people.

MS LAWDER (DFA): Yes.

MR KALISCH: Is that a constraint at the moment and if there was to be greater service provision, would there also need to be action to enhance the workforce capability?

MS LAWDER (DFA): Yes. Auslan interpreting and notetaking is one area where there's currently a gap, and if there was greater provision of support, that gap would be even bigger. Real-time captioning is another specific skill that is required and again it currently is quite expensive. A lot of captioners use Hansard reporting type equipment which is then projected on to the screen for real-time events, but we'd be hoping that with greater demand, if there were sufficient people, it may drive the price down for that, because that tends to be about $1500 per day to have a captioner, which for a three-day training course is very, very expensive. So most training providers find a reason to say no when you try to register a deaf or hearing-impaired person for their training course.

As with many service professions, they are often female dominated; that's teachers of the deaf, audiologists, speech pathologists. There are workforce cycles associated with that, and of course generally with the ageing population, those workforces are also ageing at quite a rate.

MS SCOTT: John, do you have some questions?

MR WALSH: Yes, thanks, Patricia. Good morning, Nicole. Sorry I was a bit late, but I think I only missed about the first five minutes and I've read your submission, so I think I'm pretty much across what you said. I've got a couple of questions. Can you hear me okay?

MS LAWDER (DFA): Yes, thanks.

MR WALSH: My first question relates to the issue of the $15,000 per year for preschool language training for children. I suppose my question is: what about parents who can't afford that? What happens to those children and how many children miss out on that preschool language training?

MS LAWDER (DFA): That is a good question and I'm not sure how many miss out because I can only go on the numbers of children that do attend those programs. Some of the schools that provide those services do apply a means test and they try to fill the gap from the parents with fundraising and sponsorship. Government support is another possibility but that's state based and varies widely between the different states. For example, I think in the ACT and Tasmania, the state governments give nothing to those private providers, where it can be up to 40 per cent of the funding is provided by state governments in some other states. So means testing has been applied in the past but in an environment where state government funding appears to be drying up, the schools are starting to apply that 12 to 15 thousand dollar cost across the board because they're not addressing the gap in other ways from state funding. Does that answer your question?

MR WALSH: Sort of, but I guess my impression is that most children who are born without hearing get some support somehow or other. Is that - - -

MS LAWDER (DFA):   Yes. If you get a cochlear implant, for example, you will get support provided by Australian Hearing.

MR WALSH: On that cochlear implant one, I think you said that 75 per cent of children will have a cochlear implant, 25 per cent will have a hearing aid, and presumably there's some doubling up there, so some will just go with Auslan and have no other aid. Is that right?

MS LAWDER (DFA):   Yes. The numbers who choose Auslan only are very, very small.

MR WALSH: Yes.

MS LAWDER (DFA):   But there are many people that choose a bilingual and bicultural approach which is where you use Auslan and also an aid, so you're learning English and Auslan at the same time, which is a very successful approach.

MR WALSH: Yes. I suppose my next question is a follow-on from that. That's talking about children now. So when those children get into workforce age, will most of them be able to manage in the workforce with their hearing aids and a small number with - the small number with Auslan are the ones I'm interested about and also the current workforce with Auslan, the sort of solutions that you've proposed for workplaces, same-time captioning and interpreters and Auslan interpreters, are very expensive options. What are the other options for workforce modification or getting people into the workforce, the mainstream workforce I mean? Are there any other less expensive options?

MS LAWDER (DFA):   I think there will be a lot of improvements through the Internet and the national broadband network will open up other opportunities, including, for example, interpreting and real-time captioning over the Internet and you'll then free up some of that interpreter's time because they don't have to travel. It will be remote interpreting, so they will have an hour either side where they can service another client, rather than travelling to and from an appointment, so that may assist. However, the interpreter's time is still charged at a reasonable rate for their skills and knowledge and they tend to have a two-hour minimum booking, so even if you're only booking them for a half-hour staff meeting, you've got to spend a two-hour chunk.

MR WALSH: Thank you.

MS SCOTT: Nicole, I've just got probably two more questions. The first one is - and I don't mind if you take the ACT or any other state or territory - but if I had a child with a big hearing impairment, what would be the typical life course now of that child? Are they integrated into standard schooling? Do they get specialist care initially and then transition? Could you talk about maybe what you would see as a modern experience for that child, a contemporary child?

MS LAWDER (DFA): Children are generally mainstreamed into public schools or private schools these days. In fact public schools tend to provide better support for hearing-impaired children than private schools do currently. The deaf schools were very popular but have been facing financial difficulty over time, so there are a couple of deaf schools that remain and some parents, especially culturally deaf families who prefer their children to go to deaf schools, have the same experience that they had when they went to school, but of course now that may be boarding schools because of the limited number of deaf schools or quite an amount of travel to get to school.

For mainstream schooling, students tend to have an assistant once or twice a week in the classroom to catch them up on their studies, but I can assure you that that's not enough. If you're spending four and a half days a week struggling to know what's going on in the classroom, a half a day is not enough to catch you up. They may be called itinerant teachers of the deaf who travel around between the different schools. In the ACT I think there are two itinerant teachers of the deaf who spend their time shuttling between the different schools. Most parents prefer to send their children to their local school. Their siblings may also go to the same school. There's less travel concerns et cetera. Every parent likes to believe that their child can be part of their local community and go to whatever school and do whatever it is that they would like to do. But for that child, they will probably struggle at a lot of other things; you know, sport, they can't hear whistles and instructions from the coach, all sorts of other things. They may struggle to go to the cinema with their peers, so they're still isolated, even if they are going to their mainstream school.

MS SCOTT: My last question - and I don't know if you saw the New Inventors recently but there was a product there which was about real-time captioning and again using the Internet and so on, suggesting that there had been a recent breakthrough in terms of the cost of real-time captioning. I'm not going to concentrate on that particular product, but is there evidence from overseas or even domestically that you can point to that you think there will be a radical turnaround in some of the costs of workforce participation for people with hearing impairments?

MS LAWDER (DFA): That type of captioning solution - I must say when I first saw it, I saw it demonstrated live - it brought tears to my eyes. I was so excited by the possibilities that that would open up for deaf children, to have that support in every class virtually to help them. We heard stories of children who'd engaged with the teacher for the first time in their school life. So that is the type of technological advance that the NBN, for example, can help to facilitate. It still required that workforce development to have people - it's a respeaking approach rather than a captioning machine approach, but there's still training et cetera required. But the beauty of products and services like that one is that it can provide local jobs for local people and create a relationship between the child and the person providing the service. So I do think that technological improvements will help, the same with the move to digital TV. In theory it should open up so that every program that child will watch for their media studies and English should have captioning in the future. So it's a slow process but there are certainly exciting possibilities.

MS SCOTT: Okay, thank you. I think we might thank Nicole very much for participating and providing those earlier points and wish you well.

MS LAWDER (DFA): Thank you.

MS SCOTT: Good morning, Sue. Thank you very much for coming along today. For the record, would you like to state your name and your organisation. Are you comfortable to give an opening statement, Sue?

MS SALTHOUSE (WWDA): Yes, certainly.

MS SCOTT: Thank you.

MS SALTHOUSE (WWDA): My name is Sue Salthouse and I am the president of Women With Disabilities Australia. I would like to make some general remarks. First of all, I would like to congratulate the Productivity Commission on the accessibility of the information about this study on the web site because you have an Auslan video there and the material on the web site is in alternative formats which means it's accessible, so I think as far as moving towards an inclusive world, that's a great example.

Now, WWDA is very supportive of a broad based entitlement funding scheme for people with disabilities which will provide support for those who need assistance to undertake activities of daily living and to participate, but we believe, as Nicole has said, that any such scheme needs to be firmly based on that social model of disability and also to be directly based on the Convention of the Rights of Persons with Disabilities. In particular, we look to article 4 of the general obligations which indicates to us how disability is to be viewed and catered for and we look particularly as well to article 9 on accessibility because this is the article that we see highlights what is needed to enable - and I quote - "persons with disabilities to live independently and participate fully in all aspects of life" - and we are hopeful that the development or the construction of some scheme will enable that.

Now, naturally we would like to draw your particular attention to article 6, about women with disabilities because the Convention does acknowledge the multiple discriminations which women with disabilities experience and I particularly draw your attention to the need for state's parties to take measures to ensure the full and equal enjoyment by women with disabilities of all their human rights and fundamental freedoms. Now, that taking of positive measures rather than just mainstreaming is something that needs particular attention in the development of any entitlement scheme.

We know that gender inequality is now recognised nationally and that various measures are in operation to address this, but they're not specific to women with disabilities. We know that the CEDAW concluding comments from the 34th session to the Australian government included a directive to address the inequality facing women with disabilities in the country and to collect better data, disaggregated by both gender and disability, and this is something that we also would like to see entrenched, embedded in the scheme.

The data that's publicly available shows again and again that women with disabilities have things significantly skewed against them, so that they are at a great disadvantage compared to men with disabilities and to their non-disabled counterparts. So this is why WWDA advocates in the very strongest terms that any scheme which is developed must contain gender equity as an embedded principle and must also outline concrete mechanisms to ensure gender equity in all its subcomponents of the scheme's governance and administration.

By way of rudimentary examination of the current gender imbalance in the distribution of the national disability agreement's funds for disability services, I'm actually going to dip back into the past because publicly available figures for the Survey of Disability, Ageing and Carers are not yet available and I'll have to go back then with comparison to CSTDA figures for 07-08. That's contained in the Institute of Health and Welfare reports. So if we go to compare - and I just want to demonstrate what this gender inequity that we see at present as far as service delivery means - because if we look at the numbers of men and women in the profound, severe and moderate categories of an ABS survey - and I use those terms advisedly and will come back to that - there was a much higher percentage of women in the profound and severe categories. In fact if we look at it, in the profound category, 60 per cent of those people were women, 60.2. In the severe category, it was 53.4 per cent. In the moderate category, 52.9 per cent were women. It's only when we get to the mild category that we see that flip over and there's 48 per cent of women in the mild category.

I think just looking at those percentage figures actually hides the real disparity because in number differences, there is 168,000 more women, and that's in the 03-04 figures, in those profound and severe categories. Sometimes when you look at percentages, you say, "Yes, that's right," but in real terms, that's a lot of women. So the total numbers of people in those categories in the 03-04 was over a million. Yet if we turn to this report of disability support services for the same year, there were only 187,806 service users. That's a 1 to 7 disparity. I'm wondering - I don't have the figures, I don't have the investigation - whether that is some indication of the unmet need. By 2007 and 2008, it had gone up to nearly quarter of a million. I don't have, as I said, those figures to look at the profound and severe categories. I do note, however, that using those 03-04 figures, there is a blip of more boys in the nought to 24 age group coming through, so there is that difference.

When we look at carers, we add to this disparity about the effects on the number of women with disabilities because we know that about two and a half times as many primary carers are women. So it seems to me that the greater number of women carers are looking after the greater number of women with disabilities and thus they are under-requesting services for women with disabilities compared to men.

Now, when we come to look at the allocation of disability service pensions, DSPs, the logic would tell me that those relative proportions of men and women in the severe and profound would be reflected in the DSP. But what we find is the reverse is true, in that only 38.7 per cent of DSP recipients were women. Similarly, if we look at the service users, only 40 per cent of those were women. 60 per cent of men get the DSP, 60 per cent of men are the service users, but 60 per cent of women are in those high-level categories. So unfortunately I can't tell you where those disparities lie because the gender breakdown of information in the other tables is not publicly available.

When we look also at those service user differences, there are differences between men and women with disabilities, in that there are much higher levels of men with autism, about double, but if we look at women, they are more likely to report neurological disability at about double the rate of men. When you look at the percentages of indifferent categories, the percentages of women with disabilities compared to all women with disabilities, there are twice as many women compared to men in that chronic fatigue, chronic pain, nervous system disorders, twice as many. The converse is true: there are twice as many men with disabilities in brain injury and circulatory disabilities.

The other thing that we need to look at when designing a scheme is that at present, men enter the service system at a much younger age. The median age is 29.7. About 30 is the median age for men in the service system. For women, it's 36 and a half. So men are attracting services at an earlier age as well and we need to look at why that is happening and what could be done in the construction of a scheme that would rebalance the allocation of services. The WWDA argument about gender equity has been articulated really well in the Human Rights Commission submission and we endorse their recommendations which are that gender analysis is a consideration, that gender impacts are taken into account in considering scheme eligibility and benefits, and that gender representation and inclusion at the governance area is taken into account.

I would like to talk a little, if I have time with you, about some essential changes, and that is that we put a lot of faith in the development of the national disability strategy, and having that sitting at the Prime Minister and cabinet level should ensure that all departments of government take into account the needs of the Convention and that therefore under this and with the national human rights framework that's being developed, things like accessible transport, access to premises, having hearing loops at the building stage, education, are part of whatever scheme is developed for the delivery of services. In addition we believe that employment services should also be pulled out of what is currently the service package because as per article 27, there is a state party obligation to promote the realisation of that right to work and we see that an entitlement scheme will be there to provide people with the tools that enable them to engage in the workplace, so that this becomes part of what the services enable people to do to get out in the workplace and that things like open employment services, disability services, should become just part of what is currently labelled DEEWR.

I do want to also make a plug, as Nicole did, that access to information, including information and communication technologies, is an essential part of a scheme that giving those - an eligibility regime must take this into account. Giving people the correct assistive devices to enable them to engage in the community, to engage in the workforce, is something that the funding of the scheme we believe should take into account.

I did, as I indicated in that dot point information that I sent to you, want to have a brief look at language, and in the terms of reference the use of the term "profound and severe" was too limiting and I think the discussion paper that you published has gone beyond this definition. "Profound and severe," I understand why we use that, because we're aligned to WHO classifications under the International Classification of Functioning, but in the sector, I think it has a loaded stigma and the terminology smacks of burden. Similarly, the term "carer" as a paid position robs people of independence. "Support workers" is what we're looking for.

But even in the reports that we have, those categories very closely relate to what the Institute of Health and Welfare refers to as "always or sometimes needing support" in order to undertake activities of daily living, and I think there could be a flip-over into that more inclusive terminology. I do agree though that when we're talking about otherness that it could be that terms and language get sequentially tainted, but the scheme certainly needs to look at how the use of language predetermines our conceptions.

I would look too at the possibility that self-assessment becomes a major underpinning way that this scheme is framed. Support needs can't be directly linked to types of disability and the complexity of need is related to connectedness to a network. I'd like to give you a case study that doesn't directly relate to self-assessment but Women With Disabilities does know about a woman who's got a mental health condition that leaves her without a support network. She's got agoraphobia that renders her unable to leave the house. This is overlaid by paranoia which renders her unable to access those services that she's eligible for. Her one contact is by phone to an interstate person that she trusts. So the assessment of such a person could easily say that she has a mild mental health condition but in fact it renders her unable to access the community, unable to work. The scheme needs to be designed and funded to enable some choice of assessments to be put in place and supports to be put in place. In this person's case, the removal of neglect and with proper care in place would mean that her support need diminished greatly and that there would be a cost saving in that area.

If I can talk some more about complexity of conditions, I'd like to give you another example that affects women with disabilities. Currently, disability services fund respite services and these are acknowledged to give respite both to the primary support people or carers and to the person themselves. However, the current system does not recognise people with disabilities who live independently, especially when conditions are episodic. There are times when an individual can no longer cope on their own and they need residential care for a short time after which they can return to independent living and it could be that respite would enable a person to even continue going to their workplace for a week, during which time they have respite care, because the energy-sapping tasks of shopping, cooking, washing, could be managed by someone else for a short time. I can relate to that very well and I think that needs to be looked at in terms of what respite care provisions are made.

Because many disabilities are episodic, the scheme needs to have a method whereby people can maybe bank their funding during good times or give back their funding to a governance body when it's not needed because currently we know we're in a regime where if you're allocated funding and it's going to run out at the end of the financial year, you go on this spending spree, but I think we could look at a banking system that would help people with episodic conditions.

I'd like to refer to self-assessment because that would enable a realistic frequency of assessment in a majority of cases. It recognises that people with disabilities are very often the most knowledgeable about their own conditions and needs and it enables and recognises that the person themselves is able to define the starting point of a condition. Currently, we know that job capacity assessors often don't have the experience of a particular disability. Nicole outlined where an assessment was done by somebody who had never done that particular sort of disability before and I think that building in some capacity of trust and ability for people to do some self-assessment would be a very positive move.

With funding models, we need to look at how direct funding can be made to work. It's very clear that there's so much wastage of funds as they're transferred from one agency to another under the brokerage model that's currently in operation, so the scheme needs to enable choice because not everybody will opt into or want to manage or be capable of managing their own funds, but there are many who are and who will be able to purchase mainstream services at a much greater cost efficiency.

I'd like to speak briefly about ageing with disabilities. The terms of reference specify that the scheme won't cater for people who are acquiring disabilities as a result of the ageing process. But we need to look at people with existing disabilities and there shouldn't be a 65-year cut-off because the inefficiency of putting a whole new set of services in place at age 65 means that moneys allocated just won't be efficiently used, so I think that needs to be considered. We need to consider that the very presence of disabilities accelerates the ageing process, so that, for example, incontinence, loss of dexterity, loss of balance, all have earlier onset ages when you have a disability. In particular, if we look at people who have cerebral palsy or polio, it's common for all their senses to deteriorate very much earlier and more rapidly than would be the case for someone without that condition. So I think that the scheme needs to look very closely at ageing.

The last thing I'd like to say is that inherent in the scheme must be portability of packages across jurisdictions, harmonisation of that scheme across Australia, but my main plea for women with disabilities is that we embed some gender equality into - I'm sorry I've taken some amount of your time.

MS SCOTT: No, you did very well to cover so much material in the time. We've got about seven or eight minutes left to ask some questions and it might be the case that we might want to even follow up with a few questions after that. For example, you raised a lot of statistical questions and I guess they might be things that Ralph Lattimore on our staff might have a chat to you about or John may have particular interest in that. I have a few questions but maybe I should turn to David and John and see if they want to go first. John, have you got any questions for Sue?

MR WALSH: I would be interested in exploring probably with Ralph later on the data issues that you raised. It's very difficult hearing different sets of data to understand what's happening between them, but certainly the points you've raised are put in a way that I haven't seen them put before, so we should have a look at that. I suspect that some of the datasets come in a different age range, so as people get older, of course the prevalence and incidence of disability increases severely and because there are more women of advanced ages than men, that may skew the data. But I'm sure Ralph will have a look at it and I'm certainly interested in keeping in touch with it as well.

The other point I wanted to raise is the definitional issue that you raised in switching the "severe and profound" terminology around to people who always or sometimes need support. That's an interesting twist. Within the ABS and the World Health Organisation definitions, "profound and severe" for activity limitation do mean always or sometimes need help of another person to undertake one of those core activities, that is a more positive way of putting it, so thanks for that.

MR KALISCH: I suppose I have a question about the respite care option - I suppose it's not necessarily respite care but whether someone actually providing assistance to the person within their home is actually another way of viewing it - I mean, where they don't actually need to leave their home, that actually a service provision comes in at least temporarily.

MS SALTHOUSE (WWDA): I suppose, yes, that would be an option as well but in many cases, when those respite services are set up and they're residential, it may be more efficient to just enable that person to take a break in that way, because I think there you would have economies of scale with the payment of the support workers who were around. I suppose one of the things we need to look at is that choice, perhaps, and flexibility will need to be built into systems. I'm actually talking directly from a case study known to us and that this person would have welcomed living in the inner city, holding down a very high-level job and would have welcomed a week in a hotel - maybe that would do it. A week in a hotel takes you out of your environment, somebody else does all the back work, and you can just get on with your job. So we would really like to see a widening of the experience of respite services to enable you to continue to live independently.

MR KALISCH: The other question was around the self-assessment and we've obviously heard about the benefits and advantages of self-assessment. I suppose the other question is the flipside. How do you actually deal with I suppose the incentives that people have to construct an assessment outcome that actually provides more benefit to them, because you've got to have those checks and balances in each scheme.

MS SALTHOUSE (WWDA): I think we're also looking at a transition time and changes where information and some training would be needed because nobody in the sector has really dealt with this degree of trust and this degree of being able to look at your own needs and then ask for assistance. I use this also with hesitance because I think women tend not to ask for as much assistance, so I don't wish at the same time, if I talk to build in something which may be more difficult for women, but I think that self-assessment does have great possibilities but again as I mentioned, there will need to be some choices because not everybody will be able to self-assess and it could be that in the first instance of putting this scheme in place that there would be a temptation for people to ask for a thousand hours a day, something ridiculous, whereas there would have to be built in some constraints that you could say were within - perhaps you could set parameters in which they would be able to look at an amount of support and that they could assess as to how much of that amount they would need to take up or the areas that they would need to take that up. But as I said, many of us with disabilities have a very clear idea of what support needs we have and how we would like those to be provided. The people in my personal circle who have very high support needs are very conservative, men and women. They don't want undue interference in their lives. They want to live independent, family-networked lives, and so they are unlikely to over-ask, I feel, for what supports they need.

MS SCOTT: The points you make we have heard previously, that people don't necessarily want attendant care in their home if they don't require it.

MS SALTHOUSE (WWDA): Exactly. In my personal experience, a friend who has got a very disabled child deals with up to 40 care workers, support workers, a week, 24-7 care, because this child is self-injurious, so that's a huge throughput through your house. It's like living in Pitt Street. I'm sure many people, if they could choose not to have that interference in their daily lives - and I don't mean interference in a bad way - but that intrusion - that's a better word - in their daily lives, that they would do so.

MS SCOTT: Can I come back to your remarks about ageing, Sue.

MS SALTHOUSE (WWDA): Yes.

MS SCOTT: It's early days for us, but I guess the terms of reference give us a bit of guidance, and we have to have regard to the terms of reference, but one way to read the terms of reference is the government is interested in us examining a lifetime model, so that's for the term of a person's life, but not to see it being an ageing scheme. So one interpretation, and there are many interpretations available, but one interpretation is someone enters the scheme, possibly uses the scheme on a full-time basis or episodically, but they stay in the scheme for their life, so that they effectively age in the scheme. Does that have the same level of concern, that interpretation, than what you presented in your evidence before?

MS SALTHOUSE (WWDA): I would view that interpretation very favourably, yes. I think if that is the interpretation you're able to put on it, I think, yes, people that enter the scheme for some reason earlier on in their lives, I think that's the point I was trying to make, that they shouldn't have to exit the scheme at a particular cut-off date. I think you will have considerable challenges in looking at the other side of the scheme as to what happens when people are ageing and acquiring disabilities and needing support because that will have to be encompassed in the general scheme of things. But I think if I point to what formerly happened in the Continence Aids Assistance scheme, when suddenly at age 60 you were deemed not to be incontinent any more, but that's been changed, and I think we're looking at now a tiny bite at a self-directed scheme with people who are on such a scheme being now paid the amount of money that the government used to administer and hopefully - and the government made that decision for a reason - the moneys would therefore be used much more efficiently by the people who actually need the supplies and to me, that's a tiny model of how it could work.

MS SCOTT: Okay. There's more things I could ask but we're going to run out of time. John, are you comfortable if we call it quits here now?

MR WALSH: Yes, thanks, Patricia.

MS SCOTT: Thank you very much, Sue.

MS SALTHOUSE (WWDA): Thank you.

MS SCOTT: We're now going to take a very short break because we're just a little bit behind schedule and we'll have to catch up if we can, so we might just have a five-minute break. We won't have morning tea now. We'll just have a five-minute break and then we'll invite Richard Cumpston to come forward. So just five minutes now, thank you.

MS SCOTT: Good morning. We are scheduled to have a real morning tea after Richard's evidence. Welcome to the table, Richard Cumpston. Richard, could you identify who you represent - if you're representing yourself, please indicate that - and would you like then to make an opening statement.

MR CUMPSTON: Certainly. I'm representing myself and my one-man company, actuarial company. I'd like to start by correcting an error in my first submission in April. On page 4 of that, I referred to perhaps reducing the income taper test for single persons on the disability support pension down to the 25 per cent for couples, and that was an error because I've since checked the figures and although FaHCSIA described the taper as 25 per cent for couples, it is in fact 50 per cent for both couples and singles.

In that submission of April, I noted the uneven expenditure between the states on aids and equipment and I think I quoted $4 a head in New South Wales, ranging up to $10 a head in the ACT. Now, it's very heartening that early in June, the community and disability service ministers agreed to establish a nationally consistent list of core equipment that all people with similar disabilities should be able to access. That's extremely heartening, and I believe that similar national standards could be agreed for access to all disability services and statistics published on the extent to which these standards were being achieved in each state. This would be a very useful step, an interim step, and it would reduce the risks of eventually moving to full entitlement, and I know your terms of reference refer to entitlement rather than rationing.

My submission suggested that FaHCSIA executives should accept responsibility for the slow, rude and inaccurate service received by many carers, and I quoted some examples from the Who Cares report. I've since checked Centrelink's quarterly customer service surveys - the recent ones are available on their web site - and they appear to be based on extremely small samples, samples so small as to be useless, particularly if you're trying to dig down to look at particular sectors. I've requested from Centrelink under FoI more details of those surveys and I'm still awaiting those. My strong belief is that both FaHCSIA and Centrelink have failed and failed badly in the delivery of the services through Centrelink and both should accept responsibility, but the primary responsibility has to be with FaHCSIA because although they no longer pay Centrelink, they're essentially the policy agency and the people delegating their work to Centrelink.

As a central proposition, I believe that our national disability system, which I believe is the core of what you're doing, should meet the needs of all persons with disabilities to the extent considered appropriate by Australians, so that there needs to be agreement on all sides of the fence as to what the system delivers. It's not an issue primarily for actuaries or economists, it's something that the public of Australia have to accept. Because of that, there needs to be much greater transparency about the determination of eligibility criteria for support and services. The sort of activity that is going on within FaHCSIA at the moment about the eligibility for disability support pensions needs to be much more publicly done. It needs far more transparency. The key to it is multi-party acceptance.

Now, it's very heartening that there was a Senate report on disability trusts and a House of Representatives report on carers where all the recommendations appear to have had support from all the people in the community, so that very rare spectacle of multi-party support. As a result, it's very disappointing and unfortunate that the government has so far only accepted two out of the 14 Senate recommendations on disability trusts and it's accepted in whole or part 28 of the 50 House of Representatives' recommendations on carers. If you read the government response to that House of Representatives' recommendations, you find by and large they have accepted the easy ones, the easy ones which are along the lines of "further investigate" something. Where there was actual money involved or where there was the question of service delivery, as in the recommendation about Centrelink's treatment of disability carers, the recommendation was simply rejected.

Leadership by the Commonwealth is needed to develop common standards and data systems and most, if any new funding will have to come from the Commonwealth. The major problems really arise because this is partly a Commonwealth and partly a state matter, and the state systems are essentially relics from a distant era. If we want to have anything like a national system with national standards, it has to come from the Commonwealth and virtually all the money, and certainly any new money, will have to come from the Commonwealth. So the leadership has to come from here, from Canberra.

I noted in my submission of April that improvements to the present system may be more equitable, cost-effective and politically acceptable, so that's improvements to the present system, rather than the long-term care and support scheme in your terms of reference. Now, your terms of reference are a little bit ambivalent. They start by giving background and they start by saying that the Commonwealth is essentially looking at all ways to deliver a national disability system, and then it asks you to look at a particular system heavily constrained with age-related diseases in it and one or two other constraints. I'm very hopeful that the commission will show the independence it's displayed in the past and rise a little bit above its terms of reference. Thank you for your patience.

MS SCOTT: Thank you. We have about 15 minutes or so to explore some of your points further. I have got a couple of questions, but David or John, would you like to lead off? John, are you keen to go first?

MR WALSH: Richard, I'm interested in your final comment there that the commission should rise above its terms of reference. Do you want to expand on that a little bit?

MR CUMPSTON: No, not much. You need to look at what's in your own terms of reference, but in the background - I won't waste your time looking it up now - but the background says that the Commonwealth is looking broadly at a national disability system, and then it says this inquiry is tasked to look at a particular thing, so it's clear that you are not the only game in town. You're asked to look at a particular scheme which meets those with severe and profound limitations and disease not as a result of ageing, so you're being tasked to look at a particular type of scheme, but it's only a subset. I am very concerned about that because many of the issues such as aids and appliances are issues that cut right across from the least disabled to the most. I've quoted a couple of examples at both ends of the spectrum in my first submission. Issues like disability support pensions, issues like income testing, these cut right across the spectrum, so I think it's a good thing you're doing this inquiry but I do hope the broader issues are looked at too.

MR WALSH: Yes, thanks, that clarifies it. So you're thinking in terms of income support as well.

MR CUMPSTON: Yes, and varying your terms of reference as well.

MR WALSH: I just need a bit of clarification. In your view of the current system, you said this morning that the current system is a relic of the past and other people have said that as well, but in your submission, the most recent one, you suggest that improvements to the present system may be more equitable, cost-effective and politically acceptable than the long-term care and support scheme in the inquiry's terms of reference. So I am just wondering, you feel that the current system has more potential to be fixed than a new system to be developed? Is that what I'm hearing?

MR CUMPSTON: I've quoted some of the survey data in the back of my first submission which suggests that the present entire system for the less disabled and the more disabled isn't working too badly and this theme has shown up, for example, in AIHW's disability analyses. I believe that the things that are wrong - and aids and appliances is an example of something that's not working but could be fixed fairly quickly and with very little money indeed - those things can and should be done and every step of the way should be done very carefully. One of the disturbing things about your terms of reference is it's really suggesting something quite different, cutting across what's there now. I don't think the present structure is too bad. When I said that it was a relic of different systems, I think there are unresolved problems that are still there from the closing of the residential institutions about 30 years ago, and I think those problems are largely because the states have been left to flounder with those problems. They have also had the aids problem. Aids used to be federally funded and have been dumped back on the states. I don't think the states can cope. I think there has to be real leadership from the Commonwealth and it has to pick up all these problems.

MS SCOTT: Let's see if I've got your analysis right. If you think about it as real estate, are you saying that the current scheme is a renovator's delight, a knock-down or is it just some funding maintenance problems that need to be applied? Which of those would best - - -

MR CUMPSTON: The evidence is that the scheme is not working that bad. It's rough around the edges. The core of it is not too bad. My personal view is the federal management is quite bad. The responsibility has not been accepted and there should be more management and more federal money.

MS SCOTT: So better management, better federal money and a clear commitment to national standards that go beyond aids and appliances?

MR CUMPSTON: Yes.

MR KALISCH: I wouldn't mind just picking up a little bit more about that. I suppose one of the things we've heard in many of the submissions in many of the inquiry hearings has been around a sense that governments themselves aren't carrying an adequate load and you go back to the changes that you talked about 30 years ago, that essentially the burden has been shifted on to informal carers, on to families, and I suppose the sense we're hearing is that families are really grappling with that burden, that they have taken that burden on for 20, 30 years but it's come to crunch point, that the system is actually on the verge of collapse is what we're hearing. Now, that's quite a different perspective to what you're suggesting in terms of not necessarily tinkering at the edges but some modest refinement. How can we try and reconcile those two perspectives?

MR CUMPSTON: I'm sure the people who are giving evidence to you know the problems much more deeply than I do, but looking at it as an actuary, I believe that some very cost-efficient support could be given those families. I quote the figures in my first submission. They are so much more cost-effective than professional care and they provide care which is so much more acceptable to the people receiving it. But surely, even if we spend an extra 20 or 30 per cent on those disability carers - one of the worst problems seems to be the costs of disability. If we found flexible ways to deal with that, we could have a much better system for not a lot more cost.

MR KALISCH: Perhaps going to the numbers that you're citing in your submission, could it be, perhaps reflecting on what we've just heard from Sue, that people are not necessarily very up-front in terms of stating that they have got some areas of unmet need, that they're not so forward in terms of some of the responses to surveys? Could that be partly underlying the analysis?

MR CUMPSTON: I can't answer that but what I can say is that the 2003 survey showed that needs were not being met for all sorts of reasons. It wasn't that the services weren't there in some cases, they were too proud or they didn't ask or they didn't know they were there, a whole variety of reasons. A lot of that could be addressed.

MR KALISCH: Perhaps just one more question from me. It's almost a political economy I suppose that we seem to be hearing that people in the disability sector are moving towards or trying to think about a new approach, because they essentially don't trust governments to fund a scheme fully and adequately; that they've got a sense that in the priority ordering, when governments come to make up their budgets and balance the books, that disability is sort of down towards the bottom of the priority ordering and that they're looking for a new, more independent way of funding rather than a budget funding mechanism. Do you understand that that might be an attractive dimension for them?

MR CUMPSTON: Yes, and I think quite a lot of work has been done on those disability trusts and that's one way of, say, parents to provide some security for the future. But that's only a small part of the problem. Looking overall as a money matter, what strikes me is that money is being wasted here. By not spending the money on aids, you're probably creating disability for the future and also by not meeting properly the costs of disability, you're putting more stress on those carers and you're probably causing more suicide, divorce, separation, abandonment. As economists, this is an area crying out for an economic improvement.

MR KALISCH: So it's a false economy, essentially.

MR CUMPSTON: Yes, very much so.

MS SCOTT: Certainly we have received some evidence on that, some anecdotal evidence. I'm going to take a different tack to my colleagues. One of the features of your first submission was the provision of data. Often people provide us with their life stories, their personal interaction, but yours was relatively unusual in that it was sort of data rich. If you're interested, would you like to make a few comments on approaches in relation to our data work. I mean, we're very conscious, as Sue is, that the data now is quite dated and we'd be keen to get our hands on the SDAC data as soon as it becomes available. Could you make a few remarks about data issues and the approach you think we should take.

MR CUMPSTON: Yes, I'd be grateful for the opportunity. In the past, I've read many of John's excellent reports and they all use very, very detailed operational data. All the accident compensation schemes have very rich data about the individuals and many of them put that data to excellent use. They have gone out and found areas where people weren't being supported or where money was being wasted and they finetuned their operations. Now, what strikes me in this area is how extremely little operational data there is. Both FaHCSIA and Centrelink only seem to provide a minimum of data and because the states all operate individually, there doesn't seem to be any common data. John's report with Susan Johnson for the Disability Investment Group quoted a lot of very interesting data but it was amazingly disparate on anything provided by the states. There just isn't a solid body of detailed data that as actuaries we would expect from a scheme of this magnitude.

MS SCOTT: There's always data gaps. Do you want to say a little bit more about approaches in light of that data deficiency?

MR CUMPSTON: The follow-on from that is to say that if you make changes to a system, you need to have very good data supporting it and I don't think you've got it. The bigger the change, the better the data you need. That's why I'm very much in favour of an incremental approach to the present system. The improvements should be small and should be solidly based on data.

MR WALSH: Could I ask a bit of a Dorothy Dixer, Richard. Would you support the notion of when you and I have worked with the big datasets and the accident compensation schemes, do you think a dataset like that could be built up over time and would be beneficial in that sense?

MR CUMPSTON: Yes, John, firstly, it would be beneficial but I think it would have to be built up over time because you can't correct - data systems, as you know, are very slow to establish and you can't get back data, so you'd have to build it up going forward. But you recommended a very long time period, seven to 10 years or something, with your report and you are talking in those time scales.

MS SCOTT: John, any further questions of Richard?

MR WALSH: No. The data issue is one that we could talk forever about but I'm glad you raised it; it's a very important one.

MS SCOTT: Okay, thank you very much.

MR CUMPSTON: Best wishes for your important task.

MS SCOTT: All right. This is a great opportunity to really have a cup of coffee or tea. Thank you, Richard. Now we're going to have a break and we might resume promptly at 5 past 11, please. Thank you.

MS SCOTT: Welcome back. We welcome to the table Bob Buckley. Bob, would you like to first identify your organisation and then make an opening statement, please. Mr Buckley

MR BUCKLEY: Sure. My name is Bob Buckley. I'm not actually here representing any particular organisation. I am convener of Autism Aspergers Australia and a board member of the Australian advisory board on autism spectrum disorders which are the two main national bodies for autism and I think I'm the only person that's really got both of those connections, and I'm vice-president of the ACT Autism Association. I have a son who has just turned 19 with relatively severe autism and I have a background in data analysis, information gathering, that sort of stuff, and advising governments in a number of areas.

I just want to say some things about autism and autism spectrum disorders. By definition, all of the autism spectrum disorders are severe and profound disabilities. That's the way they're defined in the diagnostic manual. Autism spectrum disorders are a relatively distinct disability. It's not always effective to sort of group them in others and I guess this is particularly shown by the way that autism is generally excluded from the mental health sector and it's distinct from intellectual disability. Only about 30 to 50 per cent of people with an autism spectrum disorder these days are diagnosed with an intellectual disability. In the case of one of the main diagnostic groups, the diagnostic requirement is that you actually have normal or above-normal IQ, that's Asperger's disorder.

The points that I want to make is currently we have extremely limited services for people with autism spectrum disorders. They're excluded from many types of services. There's a lot of services that are set up for people with intellectual disabilities and obviously many people with autism spectrum disorders would not qualify for those despite their severe and profound disability. So there's some real challenges for the disability sector in terms of dealing with autism spectrum disorders.

In 2007 the Australian Institute of Health and Welfare published its report on the burden of disease and injury. Autism ranked the second highest burden of disease for boys and eighth highest for girls. That's partly because or mainly because, I guess, autism is four times more common in boys than it is in girls. There's a 4 to 1 ratio. The Australian Institute of Health and Welfare also analysed data collected by the ABS and found that 87 per cent of people with autism have severe and profound disability which is significantly higher than intellectual disability. It makes it really, amongst boys or children, one of the more numerous and more disabling conditions.

Currently, over 1 per cent of school-aged children in Australia have a diagnosis of autism spectrum disorder. The numbers have been more than doubling every five years for 20, 25 years and we don't know why that is and we have absolutely no reason to believe that it's going to cease. But at this rate, within the next five years, it will overtake intellectual disability as probably the most common group of disabilities. It has probably overtaken intellectual disability in Queensland already, where it's known to be 2 per cent of the school-aged population.

There are massive needs for services in early intervention. I'm not sure what your interpretation is going to be of the words "care and support", whether or not that's likely to include early intervention which involves a significant clinical component. However, what is clear is that the clinical components for these people are not being met and that has a huge impact on the overall cost of care and support and the quality of life for people with autism spectrum disorders.

So one of the challenges is if autism is the second highest burden of disease and injury in this country, and yet you'll find that very few health professionals have any significant training in the area of autism at all, there is no prospect that they actually know what to do in terms of early intervention. Currently the whole field is characterised by a whole bunch of - let's put it this way: there's not a very well coordinated approach to it and there's a lot of self-interest and acrimony around what parents are told about what are the most appropriate interventions for children with autism. So when a child is diagnosed with autism, families are put in a situation of trying to interpret conflicting information from allied health professionals, most of whom have very little or no experience in actually providing the sorts of programs that the Commonwealth government Health Department advises that they need. The Health Department says that a young child with autism needs a thousand hours per year or 20 hours per week of intensive autism-specific early intervention for two to three years immediately after diagnosis. No state in the country at the moment provides that. The services from different states, providers and from the Commonwealth actually don't fit together at all. Parents are advised to go to different providers when the professional bodies say you should only go to one at a time. The situation is just appalling. It is just an embarrassment frankly.

Not all, but many children with autism spectrum disorders need significant support in education. I've got to say that the Education Departments are trying relatively hard but the big gap is in behavioural support where they need clinical attention and clinical support. In the ACT, the government has just legislated to allow schools to kick kids out of school for up to a continuous 15 days, allegedly so that they can access behavioural support. But when the government is asked in budget estimates do they provide behavioural support for children with autism, the answer is no. They don't provide early intervention, they don't provide behavioural support, and yet they're allowed to kick kids out of school, allegedly so they can get access to that. I mean, it just doesn't make any sense. It doesn't add up at all.

The amount of research being done in autism nationally is really an embarrassment, there's virtually none, and yet if this is the second highest burden of disease for boys, you would expect that something was being looked into around this and it really isn't happening. We need massive amounts of training across all of the professionals, not just care and support in terms of intervention, a whole raft of other areas. We need adult services. None of this is going to happen until we have actually have some human rights for these people in this country.

My perspective on this is that this issue is much bigger than care and support, and the care and support solutions simply won't exist unless basic things like elementary human rights are provided for, and certainly training, appropriate health support, all of those things need to be done. The challenge is that this is a growing population, doubling every five years - now over 1 per cent of the school-aged population - is an alarming prospect. Unless we can start to really believe that this is going to stop or slow down in some way, then we really need to have enormous concern on this. That's what I wanted to say in introduction. I thought you'd probably have some questions.

MS SCOTT: Yes, thank you very much. I might lead off this time. Are you able to provide now or maybe when you have time to make a formal submission any material on the impact that early intervention can have. You talked about the importance of two or three years after diagnosis that children have ideally up to 20 hours a week of early intervention therapy. We'd be very interested to know, maybe drawn from overseas studies or from experience here in Australia, I guess what you've described as the payoff, the response that the extra attention provides. Would you like to make a comment now?

MR BUCKLEY: I can probably make a comment on that at the moment. It's a bit of a contentious area because this is one of the areas of significant acrimony among professionals. There's published research, peer-reviewed research. More recently, I think last year, there was a conference called IMFAR which was the International Conference on Autism, there was a report that between 10 and 20 per cent of children given appropriate early intervention basically recovered. They had no more signs whatsoever of autism. Now, this is contentious because there's a group that say autism is a sort of a cultural thing and, "We want to have an autistic culture and how dare you take that away from us." But there's some evidence by an independent researcher that between 10 and 20 per cent had no signs of autism. For some time there's been a claim around - there was a paper published in 1987 - that really changed the whole attitude to the early intervention for autism because prior to that, it was thought that you really couldn't do very much and it was shown fairly conclusively that significant gains can be made. In 1987 there was a paper that said 87 per cent - or it was 19 out of 40, I think it was, people who were given early intervention went on to be involved in school without any aid to progress, and then the subsequent follow-up said they followed through and went on to have a life that was reflective of effectively no longer meeting the diagnostic criteria. There's debates about whether this is curing autism or recovering from autism.

I don't know whether it's 47 per cent but I've certainly seen children who make that kind of recovery with the appropriate kind of early intervention and that's been confirmed by a couple of subsequent studies. But there are still debates about whether they're somehow selecting people who are more likely to recover. So 47 per cent no longer meeting the diagnostic criteria, ie able to function fairly independently, with appropriate early intervention and only 15 per cent made no real recovery in that group, so most of the rest of the group made significant improvements.

Now, I can say that in my son's case that Warwick is still severely autistic but his support needs were significantly reduced by that kind of intervention. There are several sort of approaches to choosing people with autism spectrum disorders. What the benefits of all of those are are fairly unclear in the literature. I have a fair amount of experience in reading research literature and reading it reasonably carefully; the criteria by which they measure these things are not always the same and it's sometimes hard to interpret what they're really saying the outcomes are. But if you can get people to the point that they really don't need that level of support for the rest of their lives, and in this case we're talking about people who are among the more severely disabled, costing millions of dollars over their lives to support, then achieving those kind of outcomes in early intervention, almost irrespective of what the cost is, is cost beneficial, yet no state in Australia will do it.

MS SCOTT: Again, maybe you'll want to go away and think about whether you want to provide this material to us, but I'd be interested: did you fund your son's early intervention yourself?

MR BUCKLEY: Most of ours was funded by the ACT government but it took a 10-year court case to be going on for that to happen; I am quite convinced that without having a 10-year court battle in the discrimination tribunal we would not have got that level of support.

MS SCOTT: Okay. Do you know approximately how much the cost of your son's intervention - - -

MR BUCKLEY: He had a place in special education. The cost of a place in special education in the ACT is documented in its annual report of around currently $50,000 a year. His was probably a little bit more expensive but there was no real contribution from the health system in that which is where I believe a chunk of this - I mean, we're talking about clinical services here and the health system just abrogates all responsibility for that. So the so-called universal health system that's referred to in your documents is definitely not a universal health system, and I've got to say that I think that's a real lesson for what we're doing here, if we're thinking about a national disability insurance scheme, then we need to learn the lessons from the national insurance scheme for health that is definitely not universal. Certainly if you have a child with autism, you know how distinctly non-universal it is.

MS SCOTT: I'd be interested, given your son's progress with that early intervention, whether you have an approximate saving in cost to the taxpayer - I guess I'm trying to do, with a case study, some simple cost-benefit analysis from early intervention, and if it's cost the taxpayer $50,000 extra a year but on the longer term, it's - - -

MR BUCKLEY: He's one of the ones who is still in special education, so it's still costing $50,000 a year.

MS SCOTT: But I think you indicated that his support needs have been reduced as a result of the positive impact of early intervention. If you could give any sort of figures for that, that would be useful.

MR BUCKLEY: That's really, really hard. I mean, I've put references in my full submission - I think you may have seen a draft - - -

MS SCOTT: Yes.

MR BUCKLEY: - - - a very early draft, but this has been a massive task, trying to put this stuff together on the resources that we had. We have no support for advocacy for autism in this country. There's an indication that families' income is hit by at least 14 per cent just having a child with autism. In a year and a half, my son finishes school and I will probably have to cease work at that point to look after him. I'm not sure that either the state or the federal government is ready for me to have more spare time on my hands. I suggest that the impact and the pressure that will be put on politically will be significant, but that's a big impact for me. To have to stop work because I need to support my son because there is no appropriate place for him is a huge cost.

MS SCOTT: If you were living somewhere else in Australia, would there be an appropriate place?

MR BUCKLEY: No.

MS SCOTT: So there's no appropriate place?

MR BUCKLEY: Not really, not for somebody like my son.

MS SCOTT: Okay. My last question, and I'll refer then to my colleagues, you've mentioned in your preliminary paper the desirability of early screening. At what age should that occur and has any jurisdiction expressed interest in that?

MR BUCKLEY: I think the Liberals put it up as a policy statement in the last Tasmanian election. Other than that, I'm not aware that it has been put up on the political side. I think a few people have mentioned it. The signs of autism are supposed to be present by definition - for autistic disorder, they need to be present by age three, but it would be good to sort of screen possibly beforehand. I think screening is getting better for autism but I'm not really an expert in that area. I'd sort of have to bow out of that. I don't know what the real age would be but I could find people who would give that sort of information.

MS SCOTT: Okay.

MR KALISCH: On the data aspect, one of the things that was suggested to us in an earlier hearing was that the current mechanisms for screening and identification were not particularly good at picking up girls with autism. Is there a sense that the number of girls now being identified is accelerating at a higher rate and therefore the systems are trying to catch up? Is that a potential issue of the future?

MR BUCKLEY: I think now the diagnosis rate is about 4 to 1 boys to girls. It used to be higher in the higher intelligence groups, the Asperger's groups particularly, it used to be about 15 to 1. It probably is being picked up better amongst girls. Our diagnosis rates seem to be much the same as we see in America and the UK, Japan, across Europe. So it's hard to know. Are we going to do better than anywhere else? We're going to need a fair bit of research to do that. So if we're not doing significantly worse than anybody else, then - you know, it's hard to know. We need a lot more research to be able to answer those kind of questions.

MR KALISCH: Just on the aspect of early intervention which Patricia asked you about earlier, you seemed to suggest that there was still quite a bit of, I suppose, contention and dispute within the clinical industry about appropriate approaches.

MR BUCKLEY: I don't think there really is a clinical industry. I think that's one of the problems. If you think about the way that cancer deals with the contentions in its treatments, you have three major areas, surgery, radiotherapy and chemotherapy and although they don't necessarily get on with each other particularly well, they actually have regimes that say, "Well, most people actually need a bit of all of them," or you need one as a back-up for the others, so we really have to set up a system that's going to put individuals through a regime that delivers in all of those areas.

MR KALISCH: So is that almost pointing to I suppose more randomised control trials and testing of different compositions and evaluating effectiveness and strategies much more effectively?

MR BUCKLEY: I'd like to get some clinicians together and bang their heads together until they actually agree what needs to be done. When you're presented with a child, rather than everybody claiming that theirs is the only true way, actually sit down and look at - firstly, what the parents want is outcomes, because the treatment methods in my view are essentially very, very similar in what they deliver on the ground, but there's a difference in attitude between what they're trying to achieve that's really determining which direction you're sort of more likely to go. But this stuff doesn't come out. In the weeks after diagnosis, families are asked to make these massive clinical decisions, and given the way clinicians are at the moment, I wouldn't leave it in their hands, so families have to come to grips with all of this material and try and make these decisions for themselves without being given - you know, they don't have the skills to read the research and understand what it's about and yet that's the only way that they have any chance of actually dealing with this.

So what we need to do is actually have centres that actually offer all of the reasonable options and give parents the real information in an unbiased way. People who are not involved in particular ideologies about how to deal with disability need to be actually giving the information to families and then the families can make the choices. But ultimately we need to have a clinical system. I don't know whether you guys are interested in talking about clinical systems, the terms of reference look a bit more narrow than that, but they have a massive impact on the subsequent care and support, so I would encourage you to be interested in that area. If you're going to talk about cost, I don't see how you could ever do it without looking at it. So there's this big challenge of how you set up a system to deal with these kind of contentions, sorting out the professional response to it.

MR KALISCH: It's not necessarily a question for now but I suppose one I'll leave with you if you're going to put in a further submission or further written information, simply from your research and data background, if you could identify the sort of data items or aspects that you think might be useful for a system to have.

MR BUCKLEY: I can give you a lot of stuff about what data is out there. I mean, I've written papers and stuff about it. I was told at the last autism conference that Australia probably has the best data on children with autism in the world, so we've sort of uncovered some very good data. It's still not very good but it's probably some of the best in the world. I'm hanging out for the ABS's Survey of Disability, Ageing and Carers, as I expect you are.

MR KALISCH: Yes, we are too.

MS SCOTT: Yes.

MR BUCKLEY: I mean, that's a really useful - it's not necessarily the best available documents but it asked a whole bunch of questions that aren't asked otherwise. I don't actually have access to that data, the raw data, which would be very valuable to me, but unfortunately I don't have access to it, so I can't really look at it. I get secondary reports out of the AIHW and various places.

MR KALISCH: Thank you.

MS SCOTT: John, any questions for Bob?

MR WALSH: Yes, thanks, Patricia. Bob, thank you very much. I've got a couple of questions. One does relate back to the clinical side and while it's probably not directly within our terms of reference, intersections with the health system are. You note in your notes that most GPs don't have any idea of how to deal with a referral to an autism assessment or screening. Maybe in your further submission, the process that would be required to make that happen would be very interesting, and is it a GP education program? Is it a new workforce? Given the rate of increase in autism, it sounds to me like the current workforce of health professionals probably would struggle with the amount of work that would be required to provide across-the-board early intervention. So some discussion on how all of that might work I think would be useful to us. Do you want to comment on that?

MR BUCKLEY: Yes, I can certainly comment on that now. One thing I'll say is that during the 1990s and before my son was diagnosed with autism, I owned one of the top 10 consultancies to the Defence Department in Canberra and we did a lot of work on workforce planning. In that time, we went to both the Health and Education Departments and the Commonwealth government and said it would be a really good idea to think about workforce planning for the health and education sectors. They didn't take us up, and after my son's diagnosis with autism and my partner died unexpectedly and I wasn't able to replace him, I decided that it was not worth my while trying to continue that business, so I basically shut down the business and moved into other areas. But I do have some background in workforce planning. I would suggest that unless there are actually plans on the part of government to try and actually provide credible services for people with autism - so remember that people with autism are excluded from the mental health sector effectively. Even though all the autism spectrum disorders are in the DSM-IV, along with all the other mental health conditions, even though they're on axis 1, the same as all the other clinically treated mental health conditions, the mental health sector generally, which is getting a lot of press and doing a lot of fantastic work, I've got to say, but they still regard autism as not being their domain and people with autism are generally excluded from the whole mental health sector, in many cases, even if they have comorbid mental health conditions, which they often do, okay. So many of them have anxiety and a number of other mental health conditions. Autism was often thought to be childhood psychosis. That's what it was called before it was called autism in many cases, but we're basically excluded from that whole sector. So there is no funding for anybody to get involved in this area.

In the Helping Children with Autism package, the government will fund 12 hours of intervention for a child up to 13 years of age and then there's nothing really beyond that, which is just pathetic, and it's funded at half the rate of the early intervention, the same services that people would get for providing up to $6000 worth of early intervention through the Helping Children with Autism package. So the Medicare items are about half the rate of the average cost of a panel provision. I had one politician say to me, "Well, my kids get services through Medicare, no problem," and I was sort of thinking when you're looking at a thousand hours of service per year for two to three years compared to 12 occasions of service or 12 hours which is over the lifetime that the Helping Children with Autism Medicare item provides and parents have to provide 50 per cent of the gap, I mean, this is just not understanding the problem at all, and that's a person who's actually interested in helping in this area, so there's very poor understanding of all of this.

MR WALSH: Bob, those hours now - and this is my point I guess about the need to build a workforce - is that one on one?

MR BUCKLEY: It's mostly one on one, and what needs to be absolutely clear here is that it's not normally expected. The research does not say, "That has to be clinicians one on one." These are services that are supervised by clinicians. The ACT government - in my sort of most recent version of this that I sent you guys - has said, "We think that what we do is we're going to train parents to deliver the thousand hours." So they're expecting families to come home after a working week and deliver 20 hours a week of intensive one on one of clinical stuff, with no real clinical support, okay. So they're saying, "We're going to train you in six hours all the stuff that clinicians learn in their entire career." Now, given the current level of training, clinicians might have had a one-hour lecture on autism. Most families will attend their local autism association and within six hours will have overtaken their knowledge anyway, so it may be true that within six hours they can tell them everything they know about autism, but that really isn't going to help a child with autism.

What needs to happen is you need to have clinicians who are supervising people who are there ostensibly for this purpose already. In the integration support scheme in child care, there's supposed to be people who are to help include children with disabilities in the service, but they're not allowed under the rules to work one on one with the child. Their advice comes from centre managers who probably have no knowledge of autism whatsoever. So the worst case is that the children - you know, you can't get people who are good enough to support a severely autistic child in a child care centre under those rules, so they just don't get a service at all. The parents just can't get child care for severely autistic children. But if the people who were willing to be employed at the very low rates of pay that are involved here, most of them really want to do this sort of stuff, if they had clinical support and advice and some training to deliver this, then they could deliver 20 hours a week in child care or in settings near child care or settings that could move backwards and forwards between segregated and integrated settings. They could do this.

MR WALSH: I think we're probably running out of time - sorry, Patricia - but if you could expand on that in your submission, that would be great. I have another question. Can we squeeze one more in, Patricia?

MS SCOTT: Yes.

MR WALSH: I'm an actuary, Bob, by background, so I'm a numbers person and if you look at the prevalence rates of autism as reported by the Survey of Ageing, Disability and Carers. There's a great fall-off in prevalence beyond about age 20, and you do bring it up in your notes this morning, but at the same time, you've noted that estimated in the US, 1 per cent of people of workforce age do have an autistic - - -

MR BUCKLEY: No, 1 per cent of children.

MR WALSH: I thought I saw 1 per cent of adults as well, so - - -

MR BUCKLEY: In the UK there's a survey that went out and found people - they don't have a diagnosis today, but they found people who were living, often in quite difficult circumstances. So in the UK there's a report which is in the references that I've given in the latest version.

MR WALSH: Yes, that's the one I'm referring to.

MR BUCKLEY: Okay.

MR WALSH: So for those people, presumably the same sort of thing would be so in Australia, you would think?

MR BUCKLEY: I would expect so.

MR WALSH: Yes. My question is: those people clearly are not reporting to ABS an autism spectrum disorder, so it's probably undiagnosed. Two questions: (1) what sort of lives do those people have and (2) is it possible that the increases we're seeing in autism in children at the moment are a reporting phenomenon rather than a true incidence phenomenon?

MR BUCKLEY: Okay, two questions there. The UK report says that most of these people have never married, are living in hostels, struggling to be employed, really not the normal quality of life, the outcomes are not as good, but then they have never had any intervention. They seem to be living on the margins of our society, but it's not always the case. Last week I was at a conference in Darwin and I've got to say that there was less than 50 people at the conference and there were four people there who, if I was a bit more audacious, I would have suggested that they ought to talk to somebody about a diagnosis because it is affecting their lives, but they're obviously achieving some great things in their lives as well, so it's an interesting mix. In terms of the issue of - it's just greater awareness basically that's leading to this diagnosis.

You referred to the Survey of Disability, Ageing and Carers. In 1998 - these numbers I don't think have ever been reported but they were given to me for a paper in 2004 - the number of people with autism in the Survey of Disability, Ageing and Carers was I think 13,200 in Australia across all ages, and mostly as you said in the young group. By 2003 this had increased to 30,400, more than doubled in that five years. The AIHW reports that amongst that group, 87 per cent of the 2003 group have severe or profound disability; for intellectual disability in that survey or in their estimates, it was only 75 per cent with severe or profound disability, so they're a more disabled group than - but that's on top of more than doubling in that five years from 1998 to 2003.

Now, if it was better awareness and we were picking people up who were more marginal, then I don't think that's what we would see in the data. I don't think we would see 87 per cent reporting severe and profound disability. The US Centre of Disease Control, the CDC, and I think I've got a reference to this, or at least to them in the report - it's pretty easy to find on the Internet - they're a very, very conservative organisation and they're saying that the growth does not appear to be accounted for by greater awareness and diagnosis more in the margins. They're suggesting that it looks like there's a true increase in the number of people with autism.

MR WALSH: Do we have any ideas on why?

MR BUCKLEY: My usual comment on that is that people have destroyed their careers by suggesting reasons. The problem is that if you do say things like - and there's people who have famously suggested that it might be due to vaccines and basically they've been disbarred from practising medicine. The medical profession doesn't always get this right. The guys in Western Australia who discovered the bacteria that caused ulcers were in danger of that kind of thing, and certainly a Greek doctor had that experience prior to them. You have to be very, very careful about suggesting what might be causing the increase in autism because if you transgress conventional medical wisdom, you're likely to be ostracised in very severe ways.

MR WALSH: Yes, I understand. Thanks, Patricia. I think that satisfies my questions.

MS SCOTT: Thank you very much, Bob. Thank you for your paper and we look forward to getting your - - -

MR BUCKLEY: I'll get you some more information.

MS SCOTT: Great, thank you.

MS SCOTT: I'll now call to the table Sally Richards, please. Good morning.

MS RICHARDS: Good morning.

MS SCOTT: Thank you for coming along, Sally, and thank you for your early submission to us on your experiences. Just for the record, I understand that you're representing yourself. Is that correct?

MS RICHARDS: I am, yes.

MS SCOTT: Okay. Would you like to make an opening statement and then have us ask a few questions?

MS RICHARDS: Yes. I suppose I've been thinking about this a bit more since I sent those three notes in, those three points, and the thing that worries me I think is if the NDIS is ever going to get off the ground, then it needs bipartisan support and probably it needs to be widely supported by the community. I really worry about how that might happen. I mean, a brave government maybe would just say, "These people have a right to a life like anybody else and we're going to make sure that happens," so I think there are strong arguments, but what would the arguments be that might really persuade people who don't have a direct association with somebody with a disability?

In the ACT, I am often told by people who have the power to give services and funding and programs that actually we have no entitlement, we have no entitlement to services, to supported accommodation, to programs, to funding, no entitlement at all, and I disagree with that obviously. I always think back to when Peter Costello - you know when he said everybody should have one baby for mum, one for dad and one for the country - and I think in a way I did that. My first son, Tim, you could say I had him for me. He's an IT software engineer but he's given that up; he's now studying medicine. He's in first-year medicine at the age of 28. Of course the country wants him because he's a fantastic, intelligent, contributing young man. Then you could say then I had my next son, Duncan, for my husband, Mac, and he's a firefighter in the New South Wales Fire Brigade and of course the country wants him because he's performing a valuable community service. Then my third son, Jackson, I had him for the country, but unfortunately he is a profoundly intellectually disabled young man and actually the country doesn't want him and the country doesn't actually really care that much about him. This is my experience as the mother of my son, Jackson.

So when Peter Costello said have one for the country, what he was saying or could be interpreted as saying is, "But be very careful that you have the right kind of baby because if you have the wrong kind, then you're in trouble and the responsibility for looking after that child of yours will continue until you're dead," I mean a hundred per cent until you're dead, with very little support. Anyway, then I had to have another baby for the country, so then I had Lewis, who's a circus performer and the country loves him because he's just a fabulous young man. So I think, you know, maybe I wouldn't have had Lewis if I didn't have Jackson, so that's a wonderful outcome. But I think that we do have an entitlement, and I think about the contribution that Mac and I have made and I still make in terms of volunteer work and taxes and work, paid work and what we've contributed. As citizens of Australia, we give a lot and have given a lot and I think we deserve something back.

Bob said that he might have to give up work when his son finishes school. Well, I did give up work. I had to. The maximum level of support for me and my son, my family, was 10 hours a week. You can't really have a job on 10 hours a week. I suppose I'm fortunate in that I've got the sort of drive and determination, creativity and energy to have created Jackson's own business for him and apart from what it does for Jackson, it buys me 24 hours of support a week. Now, that is just priceless, you know. This is our fourth year. I think, "That's amazing." I still can't believe it's worked and is working. It's fantastic. Anyway, I suppose that's really all that I wanted to say just as an opening statement, so you can ask questions.

MR KALISCH: Can I ask about JACKmail. I looked at the web site and got a little bit of a sense of what services it offered but I suppose I was interested in terms of how you thought about that with Jackson, about setting up this arrangement and how he deals with it, how he provides that service, how you get customers.

MS RICHARDS: It was a long time in the planning and a long time in the preparation. When I gave up work, what I did for 10 weeks was I supported Jackson in his role as courier, because I actually didn't know if it would work or not. So I thought the only way I will know if this is going to work is if I do it. I always say that. I don't mind being Jackson's mum. You know, he's my son, but I strongly object to being his support worker. So for me to do the JACKmail run for 10 weeks was just such hard work. But the idea came to me at 3 o'clock one morning when I was lying in bed thinking - you know, thinking like Bob is, "I'm going to have to give up my entire life. What can I do? What can I do to prevent this?" Jackson has to have a job, but he can't do anything because he's very intellectually disabled. Then I thought about the things he could do. I put it all together and it just went on very slowly from there. Getting customers was indeed a hard slog. It was much harder work than I thought it would be, but it was just I suppose what any small business does when they're looking to start up a business, so I just kept persevering. We're now working at capacity and have been for a couple of years. We couldn't take on any more work for Jackson. He works until 8.30 till midday five days a week and we have our - the run is identical. Every week the run is identical. It changes a little bit each day, but Philippe is my driver and Jackson's support worker and I pay him a lot more than many other support workers I've paid because - and I'd pay more if the business could carry it, but it can't. But, you know, he's gold. Every morning when I wake up I think, "Thank heavens Philippe is coming to support Jackson." Yes, anyway, that's all, I think.

MR KALISCH: How does Jackson find this?

MS RICHARDS: I think he likes it. I'd say about eight days out of 10 he's pretty happy. He has bad days, he gets sick. I'm the back-up so that the mail always gets delivered, but if Jackson is not doing so well he stays at home with me. I've had a job where I worked from home but I've just stopped that. I'm about to go back to teach at CIT, the Canberra Institute of Technology two days a week, because I have to earn an income. Working from home was good. I'm not quite sure how I'm going to go working outside of home, even though it's only two days a week. It just means for two days a week I can't give Philippe any support whatsoever and that does worry me.

MS SCOTT: John?

MR WALSH: Yes, Sally, we have heard a lot through the hearing so far about how a new system might provide support to people and families like yourself and Jackson. Do you have any views on the idea of self-directed funding or self-managed funding and how that might work?

MS RICHARDS: I do. I think that self-directed funding is of most benefit to families. That's what I would like. Most of the families that I speak to - because I've done a lot of work with families. I mean, I know that if you talk to ACT government they will say, "We've invested this many million in disability and it's increased by this many million from that year to this year," but it just doesn't filter down to families. Now, I walk into the bureaucracy here and I look at all the people and I just think, "What on earth are you doing?" you know. I just can't imagine that you need this many people earning this much money to develop policy and procedures, but very little gets down to families. I know there's a big move towards this in many countries and it has been highly successful. I think I put a little bit in my submission about the tiny things that are done in the ACT and they have been very successful. I don't think there's been much trouble in terms of administering those.

I know that a lot of non-government organisations are against direct funding, they want block funding because they say it gives them more flexibility in how they deliver services but to me direct funding goes exactly where the money needs to go which is to the families. We still lose a bit. We lose probably a minimum of 10 per cent in auspicing fees because at the moment if you get a package it's still got to be auspiced through another organisation because I guess it's that trust thing. But if it could, like the Quality of Life grants, get paid directly into a bank account so we didn't lose anything at all, I reckon that would be really good. Are you all aware of the international review of future planning options that's done by FaHCSIA when they have gone through Sweden, Finland, UK? I just had a look at that last night and this morning and there's a couple of countries where that's exactly what they're doing, the direct funding for families.

MS SCOTT: FaCSIA has released an occasional paper and we have looked at that. I was going to go in the direction of the future. In the ACT is there any facility that you would be comfortable to see Jackson make use of, in the event that you weren't able to provide him ongoing care?

MS RICHARDS: Do you mean, does one exist?

MS SCOTT: Yes, does one exist?

MS RICHARDS: No, it doesn't.

MS SCOTT: So if you became ill what would happen?

MS RICHARDS: Look, I'm not exactly sure. I think that if I became ill he would probably go into a respite house and he would live there for as long as I was ill, or if I had an illness that I wasn't recovering from he would live there, I don't know, for as long as it took to maybe find him a spot in a Disability ACT funded support accommodation house, because government is the provider of last resort so that is what would happen, but it would be a totally unsatisfactory arrangement. He would have no choice about where he lived, who he lived with, who supported him or what he did. I just think it would be an appalling life for him because even though he's got minimal understanding of the world around him, and it's hard for Jackson to make sense of anything really, he is very aware of pain and frustration and anger and people who hurt him or harm him or deprive him of food or basic human comfort. I would hate to see that happen to him.

I didn't read my submission before I came this morning but I've been to 69 meetings now trying to sort out some accommodation for Jackson for exactly when I can no longer do this, and it's just a stunning exercise in trying to get real support and commitment from the government departments here.

MS SCOTT: No-one can provide care like the family can, but what would you think should be the sort of care that you could reasonably expect for Jackson long term?

MS RICHARDS: Well, I think every family needs a choice so what I would say that I expect for Jackson is not what many other families would want. First and foremost there needs to be a choice, and for people who write policy who say, "This model is finished, we're not having that any more. You can't have that, it doesn't fit in with current policy," when families are saying, "But actually this is really what we want. We think this is the best." There needs to be a choice without people in power saying what families can and can't have which is how we live our entire lives. "You can have this, you can't have that. You will do this, you won't do that, sorry." That's kind of how it goes.

This is in the ideal world, okay, in the best of all possible worlds for Jackson. This is what I'm working towards, because I think that you have to aim really high and then you can come down, but if you aim low then you end up in the gutter and I don't want Jackson sitting in the gutter and I don't want to be in the gutter with him. So he would have his own house, it would be his house and he would have the key to the front door. It would have three bedrooms. He would have somebody who lived there with him as a flatmate who wasn't paid but would maybe live there rent-free. There would be kind of an exchange of guaranteed presence - because Jackson needs somebody there 24 hours - for no rent. There would be a third room for paid support - Jackson is always going to need paid support, there's just no other way he's going to survive - or for family members, me, probably.

Then he would have some additional funding. The JACKmail I would envisage as continuing, but then he's always going to need additional funding for the stuff that I do - the morning showering, the shaving, the washing, the feeding, the dressing, all of that stuff, mornings, nights, weekends. He would need to have some paid support, but he would have a life that was rich and interesting and was full of people and he continued with his job. That's the other thing, that if I'm not around what happens to the business? At the moment I am the business so I have to keep that going. That's what I would see.

The thing that I'm working towards is what I call an intentional community where myself and two other families are trying to get about 10 houses built in a particular configuration. Anyway we've got a meeting on Wednesday with Housing so we'll see how that goes.

MS SCOTT: Okay. John.

MR WALSH: I just want to continue on with this a little bit, Patricia. I'm really interested in the model you've got worked out, Sally. It's almost like there's a need for paid funding for support, but what you've also achieved is an activity, a participation. I'd like you to comment a little bit about the relative value of those two things: the funding to allow just activities of daily living to be managed, but also the value to Jackson of the work he does. Is that something that we should be trying to incorporate on a larger scale for people with severe and profound - particularly intellectual disabilities?

MS RICHARDS: I do think it is something that we should be trying to do. Because of the work I've done with families over the last couple of years - and I'm just speaking from my experience, so I'm not saying this is Australia-wide - what I see in the segregated, congregated educational settings is an extreme lack of imagination and confidence in what people can achieve. There's a guy called Jeff Stronach from America, he says, "If you can do this you can work." The reason people find the whole JACKmail thing so astounding is that Jackson is cognitively somewhere between six months and 15 months. Who benefits from Jackson having a job? Everybody benefits. It's just an absolutely fabulous thing in terms of the community, because as Jackson goes about his work it can't help but educate people that here is a young man who might have significant disabilities but who is actually doing a job, with support.

Mac, my husband, used to say to me, "Well, he's not really doing the job, is he, because he's got Philippe," and I say to that, "Look, I don't know anybody who achieves something in this world without support." I know people in Disability ACT who have a PA and an EA to help them do their job, and I know they can't even answer an email because they are so busy. It doesn't matter whether you write a book or you have a baby or you get a divorce or you get a promotion, everybody is supported in this world if they achieve something. That's just the nature of humans. It's just that Jackson's support is highly visible. He needs it. He couldn't do the job without the support. It's a legitimate job. He's supported to do it but he's educating people because he's doing the job. He's educating the community. He's earning an income. Philippe has a job which he loves, I get to go back to work and I need to, that's good. The businesses actually love the service because it's a real service.

I can tell you that Jackson actually stayed at the segregated, congregated school until he was 20. I kept him there till he was 20 because I was thinking, "I don't know what I'm going to do when he leaves school. That's the end of my life as my life has been, it has to change." I didn't want to face that point. I thought, "Another year, another year, he can stay there." I had Jackson at a psychiatrist for dual diagnosis because he was literally going nuts. He was locked in a room with four other very disabled students who all exhibited quite bizarre behaviours and made weird noises and Jackson was slowly going nuts with boredom. The change in him has been - I don't believe in miracles but if I did, I'd say it's almost miraculous.

Jackson doesn't do anything in a group. He spends every waking minute with people who speak to him like I'm speaking to you now. So people speak to him, they treat him as an adult, he's treated with respect, and he's expected and encouraged to do things that it was never dreamt that he would do when he was at school. He has changed enormously. He's a much happier, much calmer, much more productive young man. There's another woman that I know quite well in America - I can't remember her name now. But anyway she runs a big disability organisation and she says all behaviour is telling you something, and if people are behaving in a way that is challenging, they're telling you that something is wrong. It just is so clear to me with Jackson that he was trying to tell me for two years that he was desperately unhappy but I just didn't listen. I didn't want to know. Now he's telling me that he's really happy.

I think that we need to think bigger, think braver and take more risks, and encourage people, right from when children are small, to think about what can be achieved not what can't be achieved. That's a long, slow process but it's one that we definitely need to encourage everybody - from parents and educators and community people and bureaucrats - to look at.

MS SCOTT: Thank you very much, Sally.

MS RICHARDS: Okay. Thank you very much.

MS SCOTT: Okay. This is last chances. You don't have to belong to an organisation, you might just have wandered along today to be here, but if you do wish to come forward just to make a comment this is your chance. We have someone. Yes. Now, just for the record could you state your name.

MS MOIR: My name is Hazel Moir and I'm here as a private individual and I appreciate that comment. I'd just like to say that I came along because I'd been doing some work in a different field in gender assessment that's brought me into contact with the National Disability Strategy Inquiry. I read the material with considerable shock about what we do and don't do for people with disabilities in Australia. One of the things I have been truly appalled by is the lack of data. I've listened to the evidence earlier today and had some conversations with people during coffee time and I would like to emphasise that there is a profound lack of proper analysis of the data. You go to the ABS web site and you see that in their surveys they're collecting data by gender, for example, but they don't present the analysis.

In the particular area that I'm interested in which is women with disabilities, we simply don't know. We don't know. We haven't known for a long time. People have been saying for a decade the data aren't there. Well, they kind of are there but somebody has to analyse them. It's the same with the AIHW data; all the data that they collect on the services delivered through the Commonwealth State Territory Disability Agreement could do with substantially better analysis and better exposure to the public, and I would very much like to see the Productivity Commission, as part of its work in this area, get that information out on the table where all these wonderful people are trying to do something to make the world better can actually have the data and use it. Thank you.

MS SCOTT: Thank you. Any questions?

MR WALSH: No, thank you for that.

MS SCOTT: Thank you for coming forward. Is there anyone else? All right. Well, that being the case I thank everyone for participating and for their attention today and our supporters and I'll now adjourn the hearings until tomorrow. Thank you.

AT 12.09 PM THE INQUIRY WAS ADJOURNED UNTIL
TUESDAY, 13 JULY 2010