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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

DRAFT REPORT ON DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT CANBERRA ON FRIDAY, 8 APRIL 2011, AT 9.05 AM

Continued from 6/4/11 in Melbourne

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MS SCOTT: Good morning, everyone. My name is Patricia Scott. I am the presiding commissioner for this public inquiry. Welcome to you all today, thank you for attending and showing interest in this inquiry. Are there any members of the media present here today and, if there are, could you please identify yourself. No? Okay. This is a public hearing and we are keen to hear from you, rather than you to listen to us, so we won't be making any long statements or anything like that, but we will be, from time to time, asking you a question or two. We have a busy schedule, so we will be asking you to stick to the time that you've allotted.

John Walsh is the associate commissioner for this inquiry and he is based in Sydney and, because of some mobility problems that John has, he will be coming in by Skype today and also by phone. So please don't be worried if you suddenly hear John or see John on the screen. He'll be joining just a little bit later, but he will also make sure that he catches up on any information he's lost, because we, of course, are making a recording today and there'll be transcript of this inquiry up on our website. So you can follow the rest of today and you'll be able to follow all the hearing days by going to our website.

While this is a public hearing, you're not required to take an oath, but legislation does expect and require you to be truthful in your remarks. If you hear something today that you'd like to comment on, please feel free to make a further submission if you've already made one, or make a submission for the first time. Submissions are not complicated affairs, they don't have to be 50 pages long; they can be as short as a very short comment. One further remark: just in recent days in the hearings, sometimes people forget that it is going to go up on the website and sometimes they are very frank in their statements about things, almost to the point that I worry they might be leaving themselves open to possible action, so I would encourage you to remember that it is actually a public transcript. Welcome to the table, Deafness Forum, and I would ask, for the transcript purposes, to identify yourselves, please, and then make an opening statement, if you wish.

MR JONES (DFA): My name is Alex Jones and I'm using a sign language interpreter today, and I'm the chairperson for Deafness Forum.

MS NEWTON (DFA): My name is Kris Newton and I'm the CEO of Deafness Forum.

MS PREECE (DFA): My name is Kirsten Preece and I'm a policy and project officer for Deafness Forum.

MS SCOTT: Thank you for coming along. We've allocated 30 minutes for your session.

MR JONES (DFA): Thank you, commissioner. First of all, thank you for having us here this morning. On behalf of the board and our members and the constituents of the deafness sector, we'd really like to say that we acknowledge the enormous amount of work that has been done so far. It has been wonderful for us to see the draft that you have presented and it is really very nice to see that the Productivity Commission has heard and listened to the responses, and we really applaud you for your work in this area.

From our point of view there are really two key principles that we'd like to address: one being inclusion for all people with disabilities; and, from our point of view, for the deaf and hearing impaired people we'd like to see inclusion and independence, to enable a feeling of empowerment and that people can be independent and included in society. The aim of that inclusion is to remove the stigma, the isolation and, because of that, the mental health issues that have been growing over the years. The National Disability Insurance scheme will enable deaf and hearing impaired people to have quality of life, a fulfilled life, from the cradle to the grave, where they can be involved in education, the work environment - the world of work and employment - entertainment, social life, transport, and the most important thing overall would be communication. Communication is the key to us achieving a fulfilled life and access to services.

I would like to remind the Productivity Commission to remember that Australia has an international obligation to ensure that the National Disability Standards are in line with the international obligations that we have for the United Nations' CRPD. The really good thing to see and what we'd like to see more of is a national approach. For so long there have been so many fragments with silos of services and it is not a cohesive service provision; the services are fragmented, there's too much rationing, some people are able to access funding, whilst others aren't. We're hoping, through the new proposal, that would be eradicated, and that would be great. A whole national approach is what we're really hoping for and we've been wishing for that for years. What is really important, from our perspective, is to have a person and a family-centred support, where we have information provided which is unbiased, and a multidisciplinary approach allowing the person or the family to make decisions and be informed on the options that are available, and provide empowerment through that process. It is about empowerment.

We'd like to see the medical model ending and adopt an Australian paradigm shift, where we can shift from a medical model to a social model. A social model is really about the person themselves and their abilities, what they can do. At the moment there are so many things that they can't do because the environment isn't supporting their needs and not allowing them those opportunities. It really doesn't matter what degree or what type of disability they have, they have a disability they have, they have a disability and they should be enabled to access that service.

I'd just like to give you a small case study involving two family members, one

Fred and one Sheila. Fred and Sheila, who have three children: one boy named Sam and two older children, Rose and George; they're at university. Fred himself is deaf and that occurred when he was 12. He had a cochlear implant when he was 12, because his deafness was occurred later, and he was employed. However, his hearing loss became more progressive and the implant processor was a little bit old. He was told, to replace the implant would be $11,000. However, the Cochlear Centre said that, because it was such an old model and it wasn't made any more, he needed to have a new implant. Fred and his wife Sheila, they weren't able to afford a mortgage, they were in rental accommodation and the costs of that were quite a lot. The other two children had hearing loss as well.

Fred was very concerned about using hearing aid services, because they are cut off at the age of 21. So he needed to ensure that he had a good quality hearing aid, so that when the service provision was unavailable he was able to still afford a hearing aid. Their son Sam, the youngest, had a severe disability, which was brain damage. With his multiple disabilities, he couldn't swallow and he couldn't suck, so he had to have equipment for suction. Fred was really reliant on his hearing for the cues of when Sam required this suction, but because of his hearing loss and the inability to afford a new hearing aid or cochlear implant, he was concerned as to how he could hear his son's needs. That family's experience altogether means that they're unable to afford a new cochlear implant, they need to support the children, who also will be out of the Australian Hearing program at the required age limit, and the quote up from the Shut Out report said, "We shouldn't require such an extraordinary effort to live an ordinary life."

In an ideal world of access, inclusion, and provision, we have the right to have the feeling of a full experience. It's a bit heartbreaking for me, because I have a family in America and 18 months ago I myself needed to buy hearing aids; it cost me $10,000 and I couldn't go to American to visit my relatives. That's fine; however, at the same time it's not. However, that's my life. For so long now I have to manage. I had to buy a baby cry alarm for $1000 in order to hear my child cry through the night. So I have a different disadvantage. I think it is about providing us options to live our lives completely and to be able to go on holidays, to be able to buy a house. Thank you.

MS NEWTON (DFA): Just to follow on from what Alex says - and I realise we've got short time and I want to leave you time for questions or comments - thank you for the opportunity to present and we're very grateful for the great work that the commission has done in terms of its draft report and we're very supportive of the recommendations overall. Obviously there is some concern within the disability sector about the issues around definitions and eligibility criteria, the "Who's in, who's out?" question, and we would certainly share that.

I think Alex raised this earlier, but we'd like to make the point that it's not the severity - in the case of sensory disabilities at any rate - of the disability; it's not measurements of which bits of the frequency, of how many ears, is actually the issue here. The issue is, is it a communication disability. In the case of someone with hearing loss, it clearly is, because it excludes them from life, as Alex has outlined. That's a critical issue for us. It's not about the medical model, as Alex again said, it's about what does it actually do to your life in terms of limiting, disempowering, or disenabling your life.

There are some issues that we will raise in greater detail in our next submission around, if I can put it more broadly: governance issues and dispute resolution processes; national standards, transparency and enforcement of those; education and the link to the education system; an innovation fund for development, certainly within our area; technology within our sector is improving pace; the potential introduction of the national broadband network is likely to have, potentially, highly significant and positive impacts for our sector, given a range of factors and variables like costs, price points, accessibility, and those sorts of things.

MR JONES (DFA):   As they are experiencing now.

MS NEWTON (DFA):   Indeed; as you are experiencing right now. We do have John back with us.

MS SCOTT: That's good.

MS NEWTON (DFA):   Quality frameworks, and we do support the recommendation that the NDIS should not be funded from a levy. We believe that this is a core government service and should come from consolidated revenue, basically. I think we might stop there and give you the chance to have comments and questions. If you don't, we have lots more to say.

MS SCOTT: Thank you very much; thank you to you both. Alex, on the way through, you mentioned that one of the issues that you were keen to see addressed was removing isolation and that would assist in improving mental health.

MR JONES (DFA):   Yes, definitely.

MS SCOTT: One of the harder questions we've asked in the overview is, where should people with mental health disabilities, mental health needs, be best assisted. For example, we've asked people to comment on the appropriate boundaries between the disability sector and the mental health sector. We're finding this quite a quandary. Often disability can lead to mental health care concerns or it can be a co-morbidity. Does the Deafness Forum or do you personally have a view about this issue? I'd welcome a conversation about this.

MR JONES (DFA): We do. For the general population, about 19 per cent of people have a mental health issue, however, in the deaf community, one out of two, so nearly 50 per cent. But I'd like to say two things about that: you're right, it's as very grey area, which is why so many people with disabilities are isolated, and because of the lack of services they don't have the opportunity to live fully, completely in society. The way I see it is that down the track, this scheme in particular and how wonderful it sounds, that that would remove those sorts of instances of mental health. So this will really help reduce and minimise the risk of mental health. So down the track, the mental health issue would reduce which means that we would be able to identify the two different areas more clearly. However, now it's very grey because there are so many people with disabilities that have mental health issues as well at this point. We do have to recognise the overlap.

MS NEWTON (DF): And if I can add there, I think that the incidence of the more obvious forms of mental health issues such as schizophrenia or something like that, I have no reason to believe that in the deafness sector, the incidence is any higher than in the population at large. What do seem to be higher are what you might call the social phobias or - - -

MS SCOTT: Depressive disorders.

MS NEWTON (DF): Exactly. So we're looking at anxiety, stress, the social phobias such as agoraphobia and so forth, and all related, as far as we can see, to the issues around isolation, lack of inclusion, stigma, inability to communicate. So Alex is absolutely right, that we foresee that in the longer term - but of course that's going to be with babies born today, so we really are talking the longer term - there's generations of people who have grown up in a different system for whom it will be in some ways business as usual because they will have acquired, for example, a mental illness as part of the process of exclusion and lack of communication in our society. So in the longer term, as Alex says, we anticipate that it would be clearer, the distinction between the two sectors. However, an interim measure is clearly going to be needed to deal with the transition from what we have now and all of the people that have suffered under that system to how we hope it will be for the future going forward.

MR JONES (DFA): Commissioner, can I also add another comment?

MS SCOTT: Yes, of course.

MR JONES (DFA): I think that we also have to acknowledge that in the report, it spoke about education being included in the scheme. However, I must say that the mental health issue often arises because of the experience of lack of services and support through the education system. So my question for the Productivity Commission would be to think about how education could be included in this or whether it shouldn't, because it's important that education is supported so people can feel empowered and people can build resilience.

MS SCOTT: Okay, thank you. John, do you have any questions for the Deafness Forum at this stage?

MR WALSH: Just one. Thanks very much, Alex. You mentioned in your testimony that you were very taken by the idea of a national scheme. One of the options that some contributors have put to us is that there's no need to do that and if we just increase the funding levels and encourage things to go on as they are, that would be another option. Can you talk a bit about why you favour the national approach?

MR JONES (DFA): I didn't really understand the second point, sorry. I understand the national scheme, but the second part, do you mean about just providing more funding? Could you explain that second point a little bit.

MR WALSH: One of the problems that people say is wrong with the system is that there's not enough funding and we've said, "Yes, funding needs to increase," but in addition to that, we think that the scheme should be brought together as a national scheme, so if you could comment a bit on whether or not you support that idea.

MR JONES (DFA): Funding is always a problem for all areas, regardless. However, I think the national approach would be a very good idea because it's a top-down approach and it would allow people choices, knowing that there would be consistency. I think increased funding is a little concerning because we'd be going back to the rationing process, so I'm a little bit afraid of that, but that's my point of view.

MS NEWTON (DFA): Absolutely. We would strongly support a national approach because of some of the issues that Alex raised in his opening statements around the fragmentation of services, the siloing of services, and that can be between government levels, as you've no doubt heard many times, so the national, state, local government. But it's also from our sector's point of view the issue of fragmentation of services between, say, the education system, the work system, the mental health system and so forth, the ageing system. There seems to be very little dovetailing or easy overlap between all those parts of the system and we are looking for a whole-of-government's multi-agency, multidisciplinary approach.

Having said that, one of our key asks is that the actual service delivery be at the community level. So it's at the local level with trusted providers in a multi-agency, multidisciplinary approach, very much centred on the person and the family, but that the funding, the structures, the standards, all those sorts of things, would be developed at the national level. As Alex said, implemented top down, but the actual on the ground implementation at the community level, if that makes sense of that dichotomy.

MS SCOTT: Yes, it does.

MR JONES (DFA): I think also there's no one size fits all. It's really based on - that the national approach would meet the needs because we have so many unmet needs at the moment and that needs to be met.

MR WALSH: Thank you.

MS SCOTT: If you're comfortable, we might finish there. Is that all right?

MR JONES (DFA): I would like to say three things, just three. The three tiers, I agree with the report on how the three tiers ensure that they work together and that all the needs are addressed, and that would ensure that everybody would know about that. There would be no loopholes. The confusopoly, as you said, it is so true, we need to ensure that there is good case management for individual people with disabilities and we need to ensure that the person knows and understands their needs and to be able to manage their life completely. Training, awareness is vital. Recruiting people who know the sector, employing people who understand deaf people, employing people who can sign, employing people with a disability to support the service, it's an amazing scheme and it would help both people with disabilities, providing the opportunity for them to work in the sector as well. So thank you very much for your time.

MS SCOTT: Thank you for coming along.

MS SCOTT: We welcome to the table Carers Australia. Thank you for coming along today. For the purposes of the transcript, we'll ask you to state your name please and then would you like to make an opening statement. We've allocated 30 minutes to your presentation but again I'll remind people that we probably will be asking a few questions as you go through.

MS REID (CA): Thank you, commissioner. Mary Reid, acting CEO of Carers Australia.

MR MOORE (CA): Tim Moore, president of Carers Australia.

MR MANN (CA): Evan Mann, policy manager, Carers Australia.

MS PIERCE (CV): And Gill Pierce, program manager policy, Carers Victoria.

MS REID (CA): We would like to make an opening statement, if I can proceed.

MS SCOTT: Yes.

MS REID (CA): Thank you very much. You will be aware that we haven't yet made a response to the interim report. We expect to do that by the end of the month. Let's begin: Carers Australia welcomes the Productivity Commission's draft report on disability, care and support. We're quite enthusiastic in fact about the main direction for reform charted in the report. The recommendations, if implemented, would greatly improve the lives of people with disabilities in Australia and their carers and they represent a major step towards our organisation's vision of an Australia where caring is accepted as a shared community responsibility.

In particular, we support - and there's four dot points here - the establishment of a genuine national insurance scheme for disability care and support, known as NDIS. That promises for the first time to give disabled people and their carers the level and quality of services and care that they need. The funding of this major expansion in support and care for people from, for the most part, Commonwealth general revenue, the consistency and assessment and service provision between states and people with the same needs and family support circumstances which the NDIS promises and the real choice that NDIS would offer a person with a disability and their carers between alternate suppliers of services and in the determination of service mix. Sensibly, this move towards self-directed funding would be phased and cautious.

Before turning to aspects of NDIS that relate more specifically to carers, let me make a couple more general observations; first of all, the coverage of the NDIS of mental illness, and this is a very significant issue. We support the commission's view that the mental health sector should pick up the specialised acute and clinical cost of long-lasting mental illness, while NDIS would cover daily support costs. We are concerned however that many people with an enduring mental illness would not seem to be covered by the scheme as currently proposed because they may not have significant limitations in any of the three core activities which have been identified as mobility, communication and self-care, yet many of these people need ongoing support, particularly with daily decision-making and social interaction. We believe there is a strong case for treating this group similarly to the intellectually disabled and this may also apply to people with an acquired brain injury. That's the first question.

The second one is around membership of the board, the governance structures that are described. NDIS would be governed by the national disability insurance agency. It would have an independent commercial board, comprising people selected for their commercial and insurance skills, as the report says. Nominations to the board would be made by an appointment panel, while the views of stakeholders, including people with a disability and carers would be provided by a separate advisory council. One problem with this complex arrangement is that it would not guarantee that at least some on the board would have a direct experience of disability or caring or a background in related areas of policy. We think that this is essential if stakeholders are to have confidence in and board members are to have empathy for the NDIS.

Just turning to the issues relating to carers, we support much of what the report says around the carer issues: the acknowledgment that a major goal of NDIS is to relieve the excessive strain on carers, the proposed inclusion of carers in the assessment process for care recipients to ascertain the level of care which might reasonably and willingly be provided by the carer and the recommendation that carers also have their own assessment, and this is a very strong point with us, the support which the report offers for carer support centres and carer counselling. The carer support centres of course were first raised in the aged care report and we have quite a lot to say around that.

We will comment on these matters in our written submission. Let me say now though that some aspects of the report show an inadequate recognition of the role of the carer. Our touchstone here is the Carer Recognition Act 2010 which was passed last year. That act contains 10 principles about how carers should be considered and treated by Commonwealth agencies and relevant organisations funded to support carers. Two of those principles are quite relevant here. Number 5 says:

> Carers should be acknowledged as individuals with their own needs within and beyond the caring role -

and number 9:

> Carers should be supported to achieve greater economic wellbeing and sustainability and where appropriate should have opportunities to participate in employment and education.

It's against the background of these principles that we reject the report's suggestion that the value of the carer payment or allowance might be included in the individualised package of a person with a disability and we have quite a strong view about that. Carer payment is an entitlement of carer's pay because their caring prevents them from supporting themselves. It's not paid to encourage informal care. Once received, the carer can of course spend the money as they please but this should be their decision and only theirs. On a more practical level, were a carer payment or carer allowance included in the individual budget, as canvassed in the report, we can only imagine that in many cases, the family carer would continue with their caring and that would be a very fair outcome.

Another area for comment here is it's well established that financial disadvantage is associated with caring. By relieving the excessive burden of care, NDIS would allow some carers to re-enter the workforce or boost their hours. The report's recommendation about amendment to the Fair Work Act 2009 for workers with children older than 18 is also welcome, at least as a first step. Even with NDIS, however, many carers will not be in paid work, so we believe the commission should consider the following: one consequence of caring over many years is an inadequacy of retirement savings. We believe there's a strong case for measures to boost the retirement savings of carers, superannuation obviously.

Another major question here is around injury. Carers often get injured while caring, another source of financial disadvantage. We support an injury compensation scheme for carers. Carers would benefit if they had access to the proposed National Injury Insurance scheme, the NIIS. Because this scheme would cover only catastrophic injury, are we right to assume that most carer injuries like bad backs and so forth would continue without compensation coverage? That's a question for the commission in fact.

Another thing is - it may be just a question of clarification - but there's a table in chapter 14 that does give us some concern. It's around assumed trends in carer numbers. In the section on offsets which is 14.26, the figures appear to imply a reduction in numbers on carer payment and allowance of over 40 per cent which is quite a significant change. Data on unit costs of care and support in 14.6 assume that NDIS covers 30 per cent of the annual cost for people aged 0-14. The assumption seems to be that the NDIS picks up the entire care and support costs for older groups, implying the complete displacement of carers, and then we note that the test doesn't quite reflect what's in the table, so there might just need to be a bit more work around that to clarify what's happening there. We would appreciate some discussion about what appears to be a very large expected movement in carer numbers arising out of NDIS.

In conclusion, let me reiterate our support for the broad thrust of the commission's draft report and we thank you for this opportunity to express our views. We'd like to continue discussions with you after the hearings.

MS SCOTT: Thank you very much. John, would you wish to ask any questions at this stage?

MR WALSH: I think we can clarify in the final report a little bit more around the costing assumptions but certainly the principle around the costing assumptions is that people would be supported to continue in a caring role but the additional funding and more efficient system, the more outcome based system, will allow that support to be provided in a much less difficult manner, I guess. Does that sort of answer your question, Mary?

MS REID (CA): I'm not sure that it does. Evan, would you like to say a little bit more about this?

MR MANN (CA): I guess it was the extent of the displacement. It's not as if we're especially troubled by it, we're just perplexed I guess about - the text talks about some displacement and the table suggests in some areas complete displacement, so I guess we were just concerned about it - not concerned, just perplexed.

MS REID (CA): Curious.

MR MANN (CA): Whereas the figures about the numbers of persons on carer allowance and benefit, they were very large reductions and I wondered whether there were reasons other than simply the displacement of - whether you were envisaging what you canvassed earlier in the report, about carer payments being able to be paid into the individualised budget. I guess that was a question too.

MR WALSH: I will go back and check the exact detail on those reductions. The issue around carer payment and individual budgets, I was a bit perplexed actually around what you said. You seemed to imply, Mary, and I would appreciate clarification - - -

MS REID (CA): Yes.

MR WALSH: - - - I mean, the carer payment is an income support payment.

MS REID (CA): That's right.

MR WALSH: Even if the Disability Insurance scheme provided the support required by the person with the disability, that payment should continue to the carer. Is that right?

MS REID (CA): That's right. This is their entitlement under the Social Security Act. It's there to support them because they don't have the capacity to generate their own income in the workforce. That's the purpose of the carer payment.

MR WALSH: But should it change from carer payment to some other income support if they're no longer providing care?

MR MANN (CA): If they aren't providing care, they may no longer be entitled to it under the social security law - - -

MS REID (CA): That's right.

MR MANN (CA): - - - in which they wouldn't get it.

MS REID (CA): No.

MR MANN (CA): But that would be the area of entitlement, we think, of how the system should work.

MR WALSH: Yes, that's my question. That clarifies it.

MS SCOTT: John, any further questions?

MR WALSH: No, that's fine for me, Patricia.

MS SCOTT: Thank you. Let's go back maybe to a few of these other points. The mental illness issue is a very perplexing one. We discussed it with the Deafness Forum. Your concern is that - we suggested in the draft report that some conditions, while we like to think about functional needs, because of the data limitations, we've ended up having to make reference to conditions. We think that's less than perfect but it's the way of the world. But some conditions are probably so severe that people would have problems with, as you said, core activities. You're proposing to extend this much further.

MS REID (CA): Yes.

MS SCOTT: You're also suggesting that some sort of superannuation scheme for carers be included, some sort of arrangement in relation to injury compensation or injury care for carers. Do you have any sense of the costs or the numbers involved? Would you be able to help us out in terms of estimating those as we go forward?

MS REID (CA): I think I'd have to say straight up we don't have actual figures but certainly we could continue some discussions beyond the hearings to do that. But I guess what we're trying to say here is that we'd like to see the definition or the coverage of the scheme widened so that there's a whole class of people, certainly within this group, that would have access to the benefits of this scheme, rather than being summarily shut out.

MS SCOTT: But that could extend to many hundreds of thousands.

MS REID (CA): Yes, I accept that.

MS PIERCE (CV): Can I say something about the difficult mental health issue. I went and did my homework a little and we have obviously discussed the issue. My understanding is that what the commission is saying is that people with very severe psychiatric disabilities will be part of the scheme but acute and clinical will sit with the Health Department. I'm assuming, rightly or wrongly, that the first category of eligibility includes people with a psych disability. However, it would be our view that there are people with significant, longstanding psych disabilities who don't have core activity restrictions but who still need help with participation with interpersonal relationships and so forth. From a point of equity, if the second category is about people with an intellectual disability who need support, then people with a psych disability would fit into that, and some people with an acquired brain injury. The dilemma in that is the potential cost increase. Is it fair to say we're sitting on the fence about that? It's a real dilemma. But from an equity point of view, if you're going to include some people with a psych disability, it probably greatly expands that eligibility category too.

MR MOORE (CA): If I may, as a carer obviously with a mental health issue, I want to make a few comments, I suppose, not only about the access of mental health consumers to NDIS but also consideration to the carers. I suppose for a long time, mental health carers have felt somewhat sidelined by a whole range of carer initiatives because the nature of caring for someone with a mental health issue is often quite different, and I think sometimes the eligibility criteria that's used to determine whether or not someone should be able to access support, both for their cared-for relative but for themselves is quite restrictive.

I suppose from my own experience, yes, my sister has schizophrenia and there have been times where she's been quite well and that's obviously something to be celebrated, but there are significant periods of time when she's not, and significant periods of time where she probably wouldn't fit into the categories that were suggested in this report, and yet it's during those times that my family probably have had to step up the most, because the system itself is also not able to support her during those lesser times.

In my situation, I come from quite a large family and my sister has a partner who takes on a lot of that responsibility, but I've also worked with lots of families who haven't had that support. I work primarily with young carers and know that lots of younger people have had to withdraw from the workforce, have had to stop school, because during those moments where mum is unwell but not unwell enough to admit that they're actually having to provide a lot of care. They often report that during those well times, they're most anxious about their parent. They're doing more monitoring, they're doing more work to ensure that mum is stable, and as a result, unable to access a lot of the opportunities that Australian society provides. So we'd be concerned about how we conceptualise caring in that and how we ensure that families in that situation can access the supports that they need because they are continuing to care, even during some of those less difficult times.

MS REID (CA): And also the issue with mental health too is that it's a bit unpredictable and episodic, so even when things seem to be going okay, you're just never sure when it's actually going to go the other way.

MR WALSH: Could I ask Tim - this is a really difficult one, maybe one of our most difficult ones because as Mary says, you open the floodgates and threaten the viability of the whole scheme - what's available to people with an ongoing mental illness are in most cases linked to psychiatric hospitals or psychological facilities. Is that right?

MR MOORE (CA): Across the country there's a whole range of community based supports that are available which are very heartening and I think are very useful in early intervention and prevention. I think, though, as the condition manifests itself, those sorts of supports become less impactful, I suppose, for the patient and then also the carer. So there are a number of supports that are available that are very localised and attempt to stabilise, I suppose, that patient and also to support them to ensure that their mental health condition doesn't exacerbate. So, yes, they are available but they're not necessarily targeted at the moment at those consumers who have lesser concerns, I suppose.

MS PIERCE (CV): I would say from a Victorian perspective because I don't know nationally that the outcome of a rationed system - like, in Victoria, we have for people with significant mental illnesses who need community support a system called Psych Disability Support and Rehab Service, something like that, and within those, some people get access to what's called home based outreach support. So a support worker would be visiting regularly - it might be an hour a week, it might be six hours a week, that sort of thing - to ensure that the person is on track, going to their sheltered work, if that's what it is, that they're taking their medication. There's also within that system some mutual support between people who have a psych disability and some residential-based rehab kind of - you know, with the aim of independent living services.

The dilemma is, in that system, they're in very short supply and I suspect because mental health competes with the ever-escalating costs of health, it's remained a very underdeveloped system. For those families, that's really extremely difficult. They can't get the help they need.

MR MOORE (CA): We should probably put it on the record that a lot of these programs are incredibly positive and have had a significant impact on the lives of consumers and therefore on carers. I suppose we're most concerned about mental health consumers and carers in rural and remote communities and also in situations where the consumer, for whatever reason, is unwilling or unable to seek or receive those supports and the implications then for the carer themselves who's realising that their relative is quite unwell. How do they seek supports during those pivotal times too, particularly if the support is attached to the care that their cared-for relative is receiving?

MR WALSH: I guess the point that emerges through that is that the continuum of care for the person with the mental illness is a health based continuum, and medication was mentioned and the community supports in the health system. So that's where our dilemma comes in and that I think is the one that we're struggling with.

MS SCOTT: Certainly your position here is clear, but if you could go further into the dilemma, that would help us. We are conscious that the federal government has a number of initiatives potentially in the pipeline coming through. We hope that maybe that will become clearer as we start to finalise our report, but certainly we welcome any further input on that particular matter. I'm just conscious of time, John. Any further questions for Carers Australia?

MR WALSH: Thanks, guys, that's very useful.

MS SCOTT: Any last comments from you? I don't want to cut you off unfairly.

MR MOORE (CA): I think generally we're incredibly heartened by the fact that carers have been identified and a whole range of recommendations have considered them in the discussion. We're very aware that over time, carers haven't necessarily been engaged in that way and we're very excited about the opportunity to work with the commission to continue to support carers. I think there's some tweaking that needs to be done in regards to assessment, there's some tweaking in regards to the way that we might position them, but overall, I think carers across the country are quite excited about the opportunities that are being presented and I think it would be remiss of us to not say thank you on their behalf for that consideration in your report.

MS SCOTT: Thank you very much for coming.

MS PIERCE (CV): And for such an incredibly difficult job, given the database that you have to work with.

MS SCOTT: The database is a problem. I wish there could be a transformation between now and July. But thank you for your time today and for your submission earlier and we look forward to getting a further submission.

MS SCOTT: I now call to the table Carers ACT, please. Thank you for coming along today. John is the associate commissioner and he's joining us via Skype and telephone so don't worry if the picture suddenly disappears; he hasn't. I remind you that we're taking a transcript because it's a public inquiry. Welcome to the table. We've allotted 30 minutes to your presentation but you might like to start with an opening statement and then say a little bit more, but anticipate there might be some questions from John and myself.

MS McGRATH (CACT): My name is Dee McGrath. I'm the CEO of Carers ACT. Today I've brought two colleagues with me, Bridget Larsen, who is a member of the board of Carers ACT but is also a family carer herself. We also have Brooke McKail, who is executive officer of the Mental Health Community Coalition here in the ACT.

MS SCOTT: Thank you.

MS McGRATH (CACT): First of all, we welcome the Productivity Commission's draft report and the opportunity to provide comment on it. We won't be repeating the points made by Carers Australia. We in the ACT are developing a collaborative ACT response to the draft report and are also providing input into the Carers Australia submission. Both of these processes are being finalised as we speak. For our presentation today, I thought I would briefly discuss the issue of service sustainability. Bridget will highlight the issues from her perspective in terms of what she hopes the scheme will mean to her and her family or families like her, and Brooke will speak about the interface between psychiatric disability and the NDIS.

MS SCOTT: Thank you.

MS McGRATH (CACT): First of all, we think it's important, thinking around our jurisdiction, we support the approach that the federal government will take responsibility on the NDIS. We would like to point out that in national funding program funding schemes usually jurisdictions like the ACT often come out quite poorly because they're based on population and size. Regardless of a state or territory's population size, however, on a practical operational level there has to be a minimum operational budget and often this makes it very difficult then for people in this territory or territories our size to be able to access and access to services can, therefore, be affected.

In the ACT we're somewhat unique in that the ACT is very much a transient population and that often equates that there's less natural supports available. We also support the approach where people with disabilities are given direct control over their own support, allowing them to access the supports they need. This approach will mean over time a more efficient market for services that people with disabilities need should emerge. That hopefully will in the services will therefore be determined by consumers rather than government. But it's critical that we don't lose sight of the importance of retaining a stable and sustainable service delivery network to provide those supports.

For non-government service providers it is really important that they can plan effectively and we really do need and service providers across the board need to have medium and long-term financial information to them to project demand, costs and investment and staff and infrastructure. If organisations are funded solely on the basis of individual support plans, there is potential for an organisation's long-term financial certainty to be destabilised while the administrative costs managing a large number of individual contracts is likely to add considerable workload and burden and taking the focus off the service delivery for those organisations.

We would just like to briefly touch on the front-end deductibles. We're really pleased that the commission has acknowledged the people who rely on natural supports to meet many of the care costs and are already contributing significantly. We agree that the NDIS should waive the front-end deductible cost where the value of this support exceeds some government-determined level. What that might be - we haven't really thought this through but some ideas that are already in place would be carer payment allowance which has already been assessed in terms of level of care that is needed. So that could be one way you might consider looking at that. But we need to caution that we don't want to see a tiered service system where individuals have little financial means and little or not family support or not able to access the full range of services because of the need to pay those front-ends. I'm going to pass over to Bridget now about what she hopes will come out of this new service system.

MS LARSEN (CACT): For the record my name is Bridget Larsen and I'm a board member of Carers ACT but I'm also a family carer. My son has Duchenne muscular dystrophy. It's a degenerative, progressive muscle-wasting condition and life expectancy to about 20 with needs intensifying obviously over that period. He was diagnosed about three years ago so I'm relatively new to it and that's the perspective that I bring to this. Around access to services the things that we need, we need things that are suitable, suitable services that are available and we've found patches of excellence and patches where we're left floundering. We're aware of their existence and certainly that's really important immediately after diagnosis. We're actually eligible for those and there's very high demands and we have been on a waiting list for a number of things despite Jamie's terminal illness and that they're also affordable.

As the Productivity Commission has picked up very sharply there it is very fragmented and difficult at the moment. The recommendations that came out, some views on those. A more centralised approach to assessments and eligibility. That would be absolutely fabulous. The amount of paperwork and the different levels and boxes that we have to squeeze in is very, very frustrating. The proposal to cover reasonable and necessary supports sounds reasonable from a policy perspective. I think it's going to be interesting to see how that is applied in practice, whether it's more subjective, how objective.

The proposal that there be no means testing and recognition of existing significant contributions in terms of family support, again most welcome. Greater choice and self-directed funding proposal, this is something that I think I put in my initial submission and really welcome. As Jamie's mother, family carer, I'm probably the only one who has a full view of him as an individual, his allied health needs, health needs, educational needs and I think that I'm probably fairly well placed to determine what will suit him as an individual, his preferences as a child and his abilities and to be able to match those to offer him as best quality of life as possible.

A forward-looking assessment obviously is appropriate particularly in a situation like ours. We have a degenerative condition. Those needs are going to intensify quickly over time and as a family we really need to be able to plan quickly financially and socially to get the relevant supports in place. My queries and concerns when I read these recommendation, just to ensure that the needs of the individual were assessed and revisited regularly. As I said, Jamie, like most children, he is an individual with his own preferences and needs; we, as family, is an individual and something that fits with him as opposed to trying to put him into a particular box. This is the way that we can offer him the best quality of life for the time that he has.

My other key concern is around market failures which Dee has already touched on. It's already difficult to get those services here, so the organisations will need to be more innovative and more flexible, often in small ways but those small ways will make such a huge difference to families like us. On service delivery, some of the same sorts of issues. What we really need as a family, reliability. For children like Jamie, he's a social being as well and we don't want just anybody coming in who doesn't fit his personality. He's entitled to build good, warm relationships over time and that makes such a difference to my ability to participate in the workforce with trust that he is being looked after by somebody who cares for him and can give him some quality there.

Quality service delivery, so the accreditation proposals obviously most welcome. As a mother you want somebody looking after your child who has a certain level of expertise. Suitability, so again not having to fit into other people's boxes. We've found various offerings that are kind of useful but it would far more useful for us at this stage if we were able to tweak it like this, but then that cuts us out of the criteria. Also affordability, again we've just gone through the process of having to build a fully accessible house with no contribution available for that in any way, so it was massive investment and we will be dragging that mortgage with us for the next 20 years. Our ability to plan so that I can participate in the workforce and pay that off depends on reliable service delivery into the future.

My concerns that came up in reading the recommendations, transitional issues. I think the Productivity Commission has a huge task ahead in transitioning. It's a very fragmented approach now to something that sounds a lot more cohesive and would work better but I am concerned about a system which is already under pressure having to take on this new framework and adapt to that framework and over the next four or five years or whatever the transitional period is, how the service delivery will be affected during that period. Again, market failure is also a concern and obviously for ourselves that children with disabilities and high-care needs are left without support, in particular jurisdictions like ACT, whether the market demand might not be sufficient to sustain a service like that and I think there needs to be some intervention to facilitate that. I'll leave it at that.

MS SCOTT: Thanks, Bridget.

MS McKAIL (CACT): Thank you. I'm Brooke McKail, the executive officer of the Mental Health Community Coalition ACT which is the peak body for community managed mental health services in Canberra. We're thrilled to be here and to be working collaboratively across the ACT with the disability sector, carers, consumers and the mental health sector to make sure that we've got a system that's meeting the needs of all our consumers here in the ACT.

I will just talk very briefly about where we see mental health fitting in in the NDIS. We do support the Productivity Commission's recommendations in the draft report that the medical and the clinical treatment of mental illness remains with the health system. But I suppose as the peak body for community mental health services we support a social model of health and see some of the most important supports as being the ones that look at a whole person, their family situation, their employment, living conditions, wellbeing and the focus there needs to be on the opportunities for social inclusion and the psychosocial supports of people with a mental illness. So we see that those supports could fit very clearly into the NDIS and that that is probably where the split should be.

I guess for us the focus on mental illness and diagnosis of mental illness it where it becomes problematic. Somebody can experience mental illness over a long period of time, they can have varying symptoms, it's not always easy to predict when those symptoms my increase or decrease, a person can cycle through numerous periods of being well and unwell. The other thing that happens quite regularly here in the ACT and I think across the country is that people experience a large number of diagnoses before they actually get one that fits best with their situation. So I think when we're looking at it in terms of mental illness it gets quite problematic to see how that might fit into the NDIS. But if we're looking at it in terms of psychosocial disability and psychosocial supports, so the actual impacts that that mental illness has on their major life activities and on their ability to meet opportunities, their employment, their education, wellbeing, fits quite clearly and isn't substantially different to the kind of support of needs that people with physical or intellectual disabilities might have. So I suppose we'd like see the NDIS framed in that framework of psychosocial disability.

Also I suppose it would avoid the problem of having to decide which diagnoses might fit into the NDIS. One of our concerns is that by making the line around people with a severe disability, something like somebody experiencing depression, for example, which is seen as a high prevalence but mild severity disorder, might actually miss out on the NDIS even though because of their situation their support needs could actually be quite high, it might be over a long period of time throughout their life and it could be the other way round with a low prevalence, high-severity illness such as schizophrenia. So if we're actually looking at the person and their support needs and the impact that that is having on their ability to fulfil their major life activities, then I think that is a clearer way.

So for us the psychosocial support and the community based supports should be included in the NDIS. The medical and clinical treatment of mental health should stay with the health system. A couple of other points around that, one of the things that was raised in the draft report is that there are a number of changes going on in the mental health system and that that could potentially impact on the decision of where mental health fits. I think a lot of the changes that are being proposed are not inconsistent with psychosocial support sitting within the NDIS. For example, the blueprint that was released from a number of experts in the field this week is recommending $3.5 billion across five years into mental health services but it's predominantly going to those community based support services supporting the psychosocial needs of people with mental illness. So I don't think that would be inconsistent with them fitting in within an NDIS, it would just be a matter of how the funding comes through, I suppose, rather than that being an exclusionary factor.

Just one other point I would like to make before we go to questions is that the idea of person-centred, so consumer-centred funding, individual support packages, we are very supportive of. But it's actually a very new thing for the mental health sector, certainly here in the ACT it's not something that happens a lot. So there would be a need to support organisations through that, as well as - Dee raised an issue of planning and budgeting for organisations. I also think there would be a need for culture change within some organisations and support to implement quite a new framework system. So I suppose there just needs to be attention to that as to how we would be supporting organisations through that change and training support and advocacy and support for the consumers involved in that. So I suppose they're my main points but happy to take questions.

MS SCOTT: Thank you. Thanks, Brooke. I've only got about 55 questions for this group, so I wondered whether I should give you a few minutes to get your questions in and just forewarn you that I have quite a few questions.

MR WALSH: I've only got one main one, but it's a big one. The issue of the intersection between psychosocial supports for people with mental illness and clinical and medical. As you said there has been $3.5 billion allocated mainly for community based - - -

MS SCOTT: I think the point was "may be allocated".

MR WALSH: Sorry, may be. But I guess where I'm struggling is the nature of those psychosocial supports might be group sessions or CBT or whatever in situation where the support is provided by usually at this stage a therapist - doesn't probably have to be in some cases - and those therapists are usually linked to the health system. So the continuum of care issue is health continuum of care, I think and I think that is where it's different from the disability system. Now, it needn't be and indeed, the issues of some people with mental illness might be very similar to people with intellectual disability or acquired brain injury. But at the moment that continuum of care sits in a medical framework. Any ideas from you on how that might pan out over the next 10 or 20 years would be useful.

MS McKAIL (CACT): I agree to an extent but I suppose the work of the community managed mental health sector is actually moving away from that medical model of care into a social model which I think fits quite well with the same supports that are happening in the disability sector. The draft survey on the NGO mental health workforce is being released at the moment and we do employ a large number of people with medical skills and medical background but the move really is away from that and it's into peer workers, so a strong consumer and carer workforce.

A lot of the community managed mental health sector does is around outreach support in housing, it's around the FamS program, so support for people getting back into employment and education and life skills and so those type of things. So I agree with what you're saying that there is an issue around continuum of care through the health system and I think one of the things that would need to be part of the NDIS would be - and this is a personal opinion that I probably haven't thought through as much as would need to be thought through - but funding of case managers that would have a very strong connection with the clinical managers within the community part of the clinical mental health sector, if that makes sense. So the community case manager and the clinical manager would have a very strong connection so there would need to be mechanisms set up for that.

But I think the move of the community managed mental health sector really is away from that medical model and therefore it sits quite well under the NDIS. Does that partly answer your question?

MR WALSH: That's good, thank you. Okay, Patricia, over to your 55.

MS SCOTT: And in seven minutes, so let's see how I go. I might have to scale it down a bit. Brooke, I wonder whether you could take a request from us to maybe draw a diagram - we've used diagrams in the report and it's a way for the team and the commissioners to try and understand where dividing lines are or how processes would work. You've talked about the health system, the clinical needs, the community needs, the socio-community needs, I would mind if you drew a diagram of really that continuum and where you see the mental health sector borderline with what you see the NDIS doing.

MS McKAIL (CACT): Absolutely. I'm quite happy to do some work - I know the Mental Health Council of Australia will be putting in their own submission but also with the peaks of the community managed mental sector around the country, we are doing some work now and really clearly defining what this sector does, so doing some work with them around how that might affect the NDIS and where the boundaries might sit.

MS SCOTT: That would be good. Also use of examples, when you go to our key features on the web site we've got a couple of cameos there, and it just would help us if you could stylise a person who would probably be in the mental health sector in your opinion and then someone who would definitely be in the NDIS in your view and then maybe someone who effectively moves between the two depending upon their clinical - it would just be useful.

MS McKAIL (CACT): Yes.

MS SCOTT: Then we could say, "Right, I think we understand where this group is coming from."

MS McKAIL (CACT): I suppose in my perspective most people would actually be across both.

MS SCOTT: I understand that and there would be an awful lot of people in NDIS already in our mind that would be across both. I imagine Jamie is very frequently talking to people in the health sector and also frequently talking to people in the disability sector.

MS LARSEN (CACT): And has developmental delays and some of the mental behavioural issues that come with it.

MS SCOTT: All right, okay. I'm going to try and compress my questions into the most crucial ones. John, Dee raised a point that we probably could explore in our report and that is that when funding is provided on a jurisdictional basis, and then Bridget said on the program basis, you end up with, because of human nature, all sorts of inequities. So the small scale of the ACT means you have to have all sorts of base funding. In WA or Queensland you have to have all sorts of attention paid to distance from major localities and so on. Whereas if you actually base things on the need of an individual, just the individual and the carers, then you're more likely to get it right and I thought that might be something we might be able to say a little bit more about in the report, John.

But now to my questions. There is this tension, I think, in your presentation in my mind about your enthusiasm for self-direct care and your concern about stable, sustainable service delivery. I wouldn't mind just seeing how we can go on this one in five minutes. The Hellenic Club next door doesn't know how many people are going to turn up for lunch but they probably make a guess, they start up the business and they make a guess and they see how things are. Then some days they might need to adjust their service, some people might need to come in part-time and so on. Businesses all around Canberra operate on a market model and they operate fairly effectively.

We have almost no market, as far as I can tell, in disability services in most jurisdictions. If businesses in Canberra can operate pretty effectively, why wouldn't it be the case that over time in an area which is clearly underserviced - where you've talked about, Bridget, waiting lists - why wouldn't it be the case that as funding doubles - not a 5 per cent increase, but doubles - that you wouldn't find more people offering innovative services, more people being able to move where they wanted and, sure, some services might get left behind because they offer really rubbishy services or services that aren't required.

I want to work out why you think we need stable and sustainable - in fact I thought you were very keen to put control in the hands of the individual or is it just advocacy services that you want to have some stability? I can see there's inherent conflict. Would you like to talk about that? We don't have a scheme underwriting Coles or IGA or clubs or - - -

MS LARSEN (CACT): My instant reaction was, using the Hellenic Club example, if they had sufficient things on the menu and things that Jamie liked on the menu or occasionally had a special offered, absolutely I would go there. But it means that they're not just offering steak, they would offer a couple of those others. So a little bit more innovative and flexible in their offerings. That's the way I would respond.

MS SCOTT: Yes.

MS McGRATH (CACT): I think this is about choice and some people will choose, like Bridget, to have their consumer-directed care and be managing that herself. Others will not want that choice. One of the things that happens at the moment, it is very fragmented because the way the funding comes in and the little narrow guidelines. So I think over time, you're right, it will be market driven and smaller organisations who are not performing, not providing the quality, they will fall off. But the few services, if it becomes fewer services, they still need to be stable and about the planning into the future because even at the moment with self-directed care and there has been some testing done nationally and it's not been very - for the organisations doing that some families are saying 10 per cent to manage this is too much. But for organisations the reality is it doesn't even cover costs.

So it has to be affordable, it has to be financially viable for organisations to provide that coordination if that's required, so that's really what I'm talking about. Also Bridget's point around - we all mentioned it - transiting to this new system. There will be organisations falling off but it's about making sure that the few that will remain can plan and be financially viable.

MS LARSEN (CACT):   Can I just add in the last couple of seconds, I think that one of the risk that you have actually highlighted is that we will lose some of those small organisations which in a way is reasonable because we're getting large organisations that are competitive but some of the small organisations are delivering really innovative services and targeted services and they're doing that really well and I wouldn't want to put that at risk because people know about Coles and Woolies so they know that's where they're going to get their groceries and it's very difficult for the small IGAs to survive.

MS SCOTT: I wish now I had not used the retail example.

MS LARSEN (CACT):   I just think that we do need to be aware that there are some small organisations who are doing wonderful things.

MS SCOTT: There are. There are very specialist providers - and I'm going back to the retail example - places that just sell handbags and places that just sell one type of hardware, places that just sell car batteries, very specialist and they operate quite well because there is enough consumers out there. So if I actually did say in the testimony I think a lot of small organisations are going to disappear it will certainly - I don't think I did but if I did, that was not actually my view. I think we could find a proliferation of services that are much tuned to what people want. We've heard around Australia about all sorts of innovations that occur when people get a chance to exercise more control.

I'm going to have to leave the challenges of asking you maybe just to take down a few things that I was keen to hear a bit more about. Any further information you can provide on people's actual experience with waiting list would be highly desirable to get. You can see how we've used examples in the report but updated examples would be good. Examples where - maybe, Bridget from your experience - reasonable needs cannot fit into existing criteria just to illustrate how that happens. It looks perfectly sensible from an administrator's point of view but, wait a minute, it's not sensible from your point of view would be useful.

Dee, I'm going to give you the challenge to try and reconcile your concern about stability and sustainability versus freedom of choice because I think that's a hard one. I think maybe I will leave that there. In terms of transition issues, I know it's hard to pin down maybe what you're after because you want something better. But if you can articulate what you're after, Bridge, I'd be welcome to see that too. I'm conscious of the time so I haven't given you a chance to answer on the go but maybe a bit of thinking time on those would be welcomed anyway. Thank you very much for coming along. John, are you okay to - - -

MR WALSH: Yes, just on that transition one, Patricia, I think that's our opportunity to actually encourage an element of innovative, perhaps smaller business. So if you could think about how that might be encouraged, I think that would be useful.

MS LARSEN (CACT): I think there is potential for existing organisations to add on some services for people with disabilities. We've got a great example at the moment of a swimming organisation and they have add-on special classes for kids. It's fantastic.

MS SCOTT: I would have thought innovation follows the money. If it's a case that governments take up this proposal, I would have thought there would be plenty of opportunity for flourishing innovators here. Thank you again for your time.

MS LARSEN (CACT): Thank you very much.

MS SCOTT: I now call to the table People With Disability Australia, Michael Bleasdale. Welcome to the table. Would you like to make an opening statement and maybe you could say just a little bit about your organisation as part of the introduction. We have assigned you 30 minutes, but at least one of us would appreciate it if you went a bit shorter.

MR BLEASDALE (PWD): I won't take much of your time, I'm quite happy to engage in answering questions. Thank you for the opportunity to come and talk here at Canberra. People With Disability Australia is a national disability peak organisation that is obviously looking at this particular issue from the point of view of all people with disability and how any new system is going to impact on them. So obviously having been tasked with analysing and providing a position, I've got quite a lot on my plate and apologise to the commissioners for not having got a written submission to you in time. I will therefore keep my statement fairly brief and obviously we will be providing a submission before the due date and the points that I raise today will be included in those.

First of all I just wanted to make the point that PWD, along with, I think, most of the other peaks feel that this is an excellent report. It seems to be comprehensive in its scope. It seems to reflect the breadth of consultation and the submissions that were made to it and we certainly applaud the Productivity Commission for having done it. It now becomes a document of great significance and becomes the basis on which we will be doing our advocacy around the new service system no doubt for the next three, four, five, however many years it takes to get up. We're also very conscious that obviously after 1 July the Productivity Commission's role in this comes to an end.

MS SCOTT: Can I just correct you there. We've got actually until 31 July.

MR BLEASDALE (PWD): You can say it was a slip of the tongue, I really meant 31 July. But really we're aware that we can make submissions to you, maybe make some amendments that we feel are important to the interim report to then reflect in the final report and hopefully bolster some of those recommendations but that really the work ahead of us is going to be lobbying for what we think needs to happen at various levels of government to make sure some of those recommendations take place.

So I won't go into what we think is good about it. I think we'll take that as read but please just accept that. So no doubt having said that it is very good, obviously we've got many points of criticism but I hope that doesn't reflect - you won't take that as necessarily an overall criticism. To get the critical points up, we believe that people with psychosocial disability or referred to as mental illness must be included in the NDIS. I note the comments from the previous speakers and I don't think I have an any more sophisticated position to put on that, but I'm quite happy to field questions about it. But we do think that, given the roll out of programs in Victoria and New South Wales, the HASI program in New South Wales, for example, we think there can be a clear distinction made between NDIS-type services and those that are going to be delivered through the healthcare system.

I was just reflecting during the last speaker's presentation about also the division between HACC and NDIS. Those of us who have been in the sector for many years know that people with disability have always had to fight in their local area to get access to HACC services and it always appears to me that HACC seems to be much more comfortable as an aged care provider rather than a disability and aged care provider. It seems that some of those allied health activities to do with HACC, to do with mental health support probably don't belong in mind, just having given it some slight thought, in the NDIS but I'm happy to take advice from those people who are more associated with the consumer movement around that. I'm also thinking that people with disability of all types are going to be accessing different types of community support and, if you like, allied health-type activities. One thing that came to mind was AA-type programs, those kinds of support. I don't see those being necessarily within NDIS just because the target group are people with disability.

So I think there is some work to be done there, but I think the division must be made and I think the final report must recommend that people with psychosocial disability coming into NDIS. For the same I think that people with chronic health conditions such as HIV AIDS also must be included in that group. I think, having spoken to people in those groups, they have the same sort of divide where they can clearly distinguish between the type of day-to-day supports that they receive and the way that they want to receive them and the kind of ongoing medical and specialist-type intervention that they would need.

On top of that I just want to say that all of those groups, once they're counted in, must have the same access to self-directed funding as anybody else who is counted in to NDIS. In fact within the global movement of people who are fighting for self-directed funding the newest and most vocal and most vibrant group are consumers of mental health services. So there is actually quite a lot of international evidence growing about how that can take place for people who - it's not generally about capacity, it's usually about the episodic nature of their particular conditions which renders it administratively complex and difficult. But I just want to have it on the record that those groups must be in.

We notice that at the beginning of the report the Convention on the Rights of Persons with Disabilities is mentioned and highlighted but we were hoping that more of the arguments around why certain aspects of the new disability service system, the NDIS, would be measured against the CRPD as a framework. I'm thinking again about the argument which I thought was very well put from a pragmatic point of view about self-directed funding but again that could be measured against our obligations under CRPD to ensure that kind of choice and decision-making is in the hands of people with disability and that would go some way towards that. Obviously that is a task for us in the peak and advocacy sector to push those aspects but we thought that having highlighted CRPD at the beginning it could actually be much more of a reference point throughout. It might be too late to influence the final report, but that would be good.

Look, on the issue of eligibility criteria, we still there is quite a lot to work through that. As long as the three-tiered proposal goes ahead where notionally everybody in Australia is in and then there's that very important tier 2 where the people who identify as people with disability are given options and that's well enough resourced. I think we would be probably happy enough to work through how exactly we establish eligibility criteria using the ICF as a framework and being very mindful of the importance of subjective identification and then some checks and balances around that. So I don't necessarily think we've got very strong recommendations to make to the commission on that one.

One point we did want to make though was with the new disability insurance agency we would strongly recommend that the staff who are working locally with people with disability and families and carers are not classified as case managers but instead adopt the role of the local area coordinators which has been so successful in Western Australia. The nature of these roles is to shape resources, it's to work with the individual and not necessarily merely to place people into a set of pre-established service options and I still think that a lot of the language within the report talks about service options and I think we still get forced into a discourse about service options which I don't think is really at the heart of what the new disability insurance scheme needs to be all about. It's actually about working with the individual, trying to place the individual within the community, honouring the individual's ambitions and then matching the resources to make the best and most efficient supports assist them towards those ambitions and goals.

In those jurisdictions where much more individualised supports have been put in place people have a very strong aversion to the term "cases", they are not cases, they are people, and the idea of management, as I said, is more about placing people into pre-set options and not thinking creatively. The other thing is that when we do engage with this how do we differentiate for those people who have to engage with the health care system and other systems. I think we have to take it as read that they will continue - and it might be appropriate - with their case management systems. If we have case managers and too many systems it's going to get very complicated. So it's not merely a semantic point, I think it actually becomes quite important.

We are not convinced by the argument that the role of people with disability in the governance of this scheme should be one of a number of groups within a larger advisory body. We think that it is vital that the rhetoric of valuing the expertise of people with disability - and I think the point was made also about people who are families are carers in the previous submission - and the expertise that they bring to the design around supports, be supported by creating decision-making roles within NDIS for people with disability. We accept the arguments about the need for financial insurance and management expertise, but the business of NDIS will ultimately also be about delivering disability supports and I believe that that expertise currently is missing.

People with disability in the peak and member organisations must be involved also in the development of workforce development and training initiatives, which will need to be implemented to ensure that adequate quality support is provided to support recipients. That is building on the idea that people with disability and groups such as PWD and other peak organisations have many, many years of experience and expertise to offer and we don't really want to be sidelined to just putting submissions in for this kind of inquiry. We want to be actively engaged in the next steps and throughout, and that's another reason why we want to have a much stronger role around decision-making and governance.

I'll try and cut to the chase. In terms of the aged care system, ideally we think the aged care system and the new NDIS after a number of years should merge and there needs to be a continuity of care. But we accept that it's difficult, given the recent nature of the inquiry into aged care and the kind of recommendations and what is going to flow from that, and it might muddy the waters of changing the disability service system. We also acknowledge that there are recommendations which will enable people with disability entering the aged care system who will then be able to follow that through. So that is to be welcomed. We are not clear about whether or not the recommendations of the commission around self-directed funding are applicable to people whose capacity might be in question.

I just want to put on the record that in fact a lot of the mechanisms which have been highlighted in the report under the disability support organisations supports, which we would term "brokerage," have been developed to assist people with intellectual disability and mental health problems, and they have been proven to be successful in those kinds of arrangements. So we would strongly say that anybody who is eligible for tier 3 needs to also have the eligibility for the self-directed funding, and I am not convinced around the recommendation about someone on the NDIA staff being the final arbiter of who can and who can't, I think we need to work through that.

In terms of up-front deductibles, I can understand from an economic point of view why people who receive informal care might be subject to some waiving of those fees, but it doesn't make terribly much sense for people who don't have those kinds of supports to be hit with an impost of an up-front deductible towards the cost of their care. In terms of disability employment, we think if the employment system is to be funded and overseen by NDIS then there's quite a lot of work to be done for it to free itself from what we see as the policy shackles of Job Services Australia and Centrelink type arrangements at the moment, I don't think they work terribly well together.

In terms of the legislation that's needed, we feel that it must quite clearly enshrine the rights and principles of the convention as well as be incredibly pragmatic, and that would be another opportunity I think to use the CRPD to set its outcomes, goals and targets. In terms of complaints, we agree that there should be two systems. There needs to be one that deals with appeals and other kinds of complaints around the system itself, but we would strongly recommend that there be some kind of independent complaints-handling mechanism with quite significant powers that is going to be able to look nationally at complaints of people about service providers and about disability support organisations as well - - -

MS SCOTT: You didn't think the statutory officer was sufficient?

MR BLEASDALE (PWD):   Looking at that, I thought that might be more for the internal complaints about NDIA.

MS SCOTT: It's also about service providers.

MR BLEASDALE (PWD):   I wasn't sure. I think what we're saying is that we need two separate ones, because I imagine there'd be quite a lot of initial complaints or appeals about access, to tier 3 in particular, and that we might get bogged down with those. The actual complaints are going to be very important, because we're going into a much more market-orientated support delivery system. It's going to be really important that we have got a very powerful complaints body out there that is able to check up and take some effective action against people who are not providing the kind of supports people need.

MS SCOTT: Given that the process is where the NDIA is effectively assessment, and then a payments mechanism - well, there's quality control as well, but not the direct employer of the services - I'm not sure how you could make the distinction between the two. But anyway, I welcome your views on that.

MR BLEASDALE (PWD):   Maybe I can put that in the submission, be a bit more clear about why the distinction needs to be made. I just think there needs to be some independence - - -

MS SCOTT: You could call the independent statutory officer an ombudsman, if you like, but the text does say "independent statutory officer".

MR BLEASDALE (PWD): Yes. A concern is that we still talk about specialist accommodation options. In our submission we did talk about the need from here on to be talking about "housing for people with disability," and we still maintain that. We think that again the convention really tells us we should be moving away from the idea of segregated specialist models. I understand the practicalities that some people with high support needs require substantially modified accommodation, but as soon as we talk about specialist accommodation models we start talking about people not as individuals, we talk about them in terms of their impairment types and how we can lump people together with similar impairment types and a lot of those issues of choice and control go out the window.

It is a big challenge, I acknowledge that, but it is something we have got to start talking about, for a new system. NDIS is primarily about the provision of funding and support, and we need to be engaging at tier 1 or tier 2 very substantially with public and private providers of housing so that modifications become much more affordable, because housing is built to a certain standard. These kinds of modifications, so even people with very significant medical needs and ongoing 24-hour support can live in regular housing in the community, is a really important point. It's something that I have seen with my own eyes in other jurisdictions with people who have had access to individualised funding, and they don't talk any more in terms of "specialist accommodation". Look, I'll leave it at that. My apologies, I took a lot longer than I thought. I'm happy now to engage in questions.

MS SCOTT: Michael, if you could give us a concrete example of one of these places you have seen which is providing high care, 24-hour support, a real life example, that would be very useful.

MR BLEASDALE (PWD): It's very ordinary, so if I tell you you probably won't be terribly impressed. It was in British Columbia. It was an initiative that was provided to a peak organisation to assist people with physical disability and 24-hour medical needs to move out of the institutional setting in which they were living in and into the community. It basically just bundled up the money that was being spent on them in the institution, which was in the region then - this is 10 years ago - of CAD$100,000 per year, to then use that money in whatever way the person saw fit to build their support networks in the community. One thing they have in this particular city is cooperative housing, which is not built to fully-accessible standard but has adaptability standards built within it. One of the features that I noticed was cupboards which are moveable; so you can have them up here, or you can have them down there, very simple stuff.

Moving one particular person who was ventilator-dependent 24 hours into adaptable cooperative housing was very straightforward, there wasn't much in the way of adaptations that was needed. I 'm not a technical person, so I can't give you the details, but there were some clever adaptations made to televisions, phone equipment, that kind of thing, to enable independence there. There was a good deal of money spent on day-to-day supports, but there were periods of time where the person was able to live without assistance. So they were able to become much more flexible about the way that they used that significant amount of money to then pay for the assistants. It tended to work with having a principal assistant, who was someone that was known and trusted, who could then provide a lot more supervision and advice to the other ones.

MS SCOTT: That's a good example. I am going to give you some harder homework. I am interested in what would be the alternative arrangements for someone who would be associated with 24-hour care - because of self-harm, non-verbal capacity, severe intellectual disability - and how you see that a person could separate care entirely from housing.

MR BLEASDALE (PWD): Sure. I did meet somebody else who was a person who when living in the group home type environment was associated with violence, self-harm, was bipolar, was faced with a physical disability. The first argument to make is that when you congregate people characterised as you have then that actually causes more problems. So the idea of having specialist accommodation based on characteristics, which was my point, doesn't actually stack up there. This person was living in ordinary accommodation, actually two-storey accommodation, with a co-resident; the co-resident was living upstairs, they were living downstairs. So any issue about risk management and violence was sort of taken care of by the person who was the co-resident being able to remove themselves fairly effectively and quickly from the situation, and having the attendant supports available in the community.

MS SCOTT: See, I'd call that supported accommodation.

MR BLEASDALE (PWD): No, this was a rented house in the community.

MS SCOTT: Yes, all right. That's what we are envisaging as supported accommodation.

MR BLEASDALE (PWD): Okay.

MS SCOTT: So I think maybe it's just the titles that are separating us. John, do you have any questions for Michael? I'm just conscious of time.

MR WALSH: Yes. Michael, in your written submission I'd invite some discussion around how you suggest we reconcile the rights idea with an ICF-type assessment, if you like, for reasonableness. While we're recommending a considerable enhancement, it's not unlimited. So we need to assess some sort of benchmarking;

what is a reasonable a request for support, in a budget way, in a financial way. So we need some way of, if you like, setting benchmarks.

MR BLEASDALE (PWD): I'll put some thoughts to that. Initially, one of the things I was very heartened by in the report was the notion of the tier 2, and I think a number of people with fairly significant support needs will look at the possibilities of being supported through tier 2, because in their minds it is about having access to what is available to everyone else in the community, and that's not just a set of nice principles, it's actually how people want to live. It's not just a referral service, the local area coordinator system works by actively trying to shape and re-shape those mainstream services that are available in the community, and that kind of proactive re-shaping in many instances leads to less of a need for the specialist provision of tier 3 services.

There is a wonderful example in Western Australia of a group of people who have fairly significant intellectual disability, who, through negotiation with, I think, Homeswest, in a regional town were able to live without any specialist support, just with the oversight of the neighbours, who were then provided with subsidised rent by Homeswest. From memory, that has worked for about 15 years. Those are the kinds of things that are possible, and, to my mind, that's shaped in the tier 2 element of it. So that's one element that we'll be looking at, to make sure there are adequate resources for that.

MR WALSH: That would be useful to get in a written submission.

MR BLEASDALE (PWD): Okay.

MS SCOTT: Thank you for your time, Michael.

MR BLEASDALE (PWD): Thank you.

MS SCOTT: We actually are going to now pause for five minutes. We'd like to see if we can get Skype back operating as we'd like, John. So we're just going to take five minutes and come back about 5 past 11, whether it's working or not. Thanks, John.

MS SCOTT: Welcome to the table, Sue Salthouse, president of Women With Disabilities Australia. You have got a very speedy 15 minutes allotted to you. Your time starts now.

MS SALTHOUSE (WWDA): Okay. Thank you very much. We would like to thank you for the report and acknowledge the high level of strategic thinking that has gone into that and for the details on those aspects of the scheme. And for delivery of your three kilogram baby, on time. As you know, Women With Disabilities Australia bills itself as a human rights, disability rights and women's rights group. I am not going to go back through, but you'd remember our submission on gender in the national disability care and support scheme. We do maintain though that our obligation, under human rights conventions and instruments, does commit the Australian government to promoting gender equality, and that comes through too in the UN Convention on the Rights of Persons with Disabilities.

I'd like to reiterate that we do believe this implementation gap between what we ratify at a UN level and what we implement at a domestic level is still operating. In the report you have mentioned the gendered nature of the paid support and carer workforce and the gendered nature of the natural supports that are available, but I think that we need to make greater emphasis on the gendered nature of disability and the intersectionality of disability and sex discrimination. There is a different experience of disability between men and women, and you have acknowledged that and been able to see that when you have looked in the context of the indigenous Australians.

Although that's a different cultural context, that gendered nature does pervade everything that affects women with disabilities. Unless we actually name where gender must be analysed and where it will impact in whatever the final report is, our experience is that it continues to be overlooked. We are now getting to the stage in other considerations, like the Covention on the Elimination of Discrimination Against Women, and that is flowing down to many of the documents coming out of the Australian government, where we are now named in a list, and that is the very beginning of getting policies and programs that will take into account our needs as women.

One of the most important aspects of the scheme, which you have picked up in the draft report, is that need for collection of data, baseline data is missing. As a minimum, we think that that data collection in the authority, the NDIA, should come down to getting that gender disaggregation publicly available as well, so that there's more transparency in what is happening within the insurance scheme. Because people with disabilities will be able to purchase mainstream support services, we think that it's not quite clear from draft report how mechanisms will be set up. They must be set up to also collect that data from the external providers and it can be incorporated into what the ongoing policy production and operational production from the authority will become.

I would also like to look at the fact that we need to maximise the social and economic participation of women with disabilities, and I think that they will be very highly concentrated in tier 2, but I'm just not quite sure that there is sufficient money in tier 2 to give them the sorts of supports or the sorts of cross-referrals that are going to be necessary, in that I think where we are putting in tier 3, looking at it particularly through the international classification of functioning, if we're looking at those activities of daily living, there's a great worry that women will not get the minor supports necessary for their social and economic participation. So I'd just like some more attention to that, because we think that women with disabilities often fall through service gaps.

If you look perhaps at the situation of a woman with disability who has a new child - I have been in touch this last week with a woman here with spina bifida, who has a small baby - the health system doesn't have expertise to give her the support she needs; and if the disability service system it's giving support to eligible persons, she wouldn't be eligible and she is going to fall through the gaps. So we just need some tinkering with how those cross-referrals happen between health and disability and how there's a seeding of expertise between those systems.

Where we are concerned too is with whether women with muscular skeletal disorders and affective disorders and chronic disease are going to be perhaps not eligible for supports. Women with disabilities are over-represented in identifying with things like RSI, and what happens with another gap is that we could be in danger of reinforcing the current gender bias in the medical profession, through forcing them back into the medical system, because there are statistics available that things like RSI are still largely written off as just a minor condition or a made-up condition. So that's a difficulty for us.

I'd like to also take up on an example that you asked Michael Bleasdale for, and that is that we have an example here in the ACT of somebody who was not on a ventilator but on chin control, who was living independently in a house, and funding was used to put into an automatic control unit so that he could from his chair operate his phone, his door, his television, and that worked really well. I think that the people who were more scared were his support workers, who came in I think a minimal number of times a day to lift him.

We also have an example here in the ACT of somebody with 24/7 care who is living with some natural supports and some community supports. I'd like to mention too the exclusion of public housing from the scheme; how we're going to make sure that the scheme won't trap women with disabilities in specialised accommodation - and we don't like that word either - because women with disabilities have a great deal of difficulty leaving special accommodation to get into the public housing system because they have low income and because they don't have the necessary supports.

The other thing I'd like to comment on is how we can guard against an over-reliance on the international classification of functioning when we look at the supports that people need, because that skews the assessment and the eligibility towards activities of daily living, whereas women will need other supports, like supports for parenting, supports for access to employment and for community inclusion. A danger with women is that they tend to be stereotyped as not needing support for activities of daily living, whereas women themselves underestimate their support needs in activities of daily living. The parallel that I would draw is women in the employment system when they are negotiating a contract undersell themselves, and the same will happen here.

MS SCOTT: Sue, you've used the example of employment contracts, but do you have any data regarding the statements about women being under-represented in relation to daily needs? If you have some data on that, I would welcome getting that.

MS SALTHOUSE (WWDA):   I know in my first consultation with you we looked at the allocation of support services through the data that is available in the AIHW, supports on CSTDA payments, that's one of the areas where there's a skewing towards men. There's more men identified in the system, getting daily living supports, whereas when you look at the ABS statistics there's more women with disabilities. Remember, last time I talked to you I tried to do that cross-matching, but it was a bit of an orange and apple situation.

We can see on those Surveys of Disability, Ageing and Carers that there are more women in particular areas, and yet when we look at the service delivery and the support services we see that there are more men being supported. I can come back to that and have a closer look and give you some more information on that. But that's one of our big concerns, that's where data lets us down, we can't look at where women are getting support services elsewhere and compare it. There's a little bit in the 2003 SDAC, but we're waiting for the 2009 SDAC of course.

The only other point that I would like to make is that, under the governance and financing of the scheme, we would like consideration of positive discrimination throughout all those mechanisms, in all areas of governance. I think appointments to the board itself need to be guided by the Sex Discrimination Commissioner's Gender Equality Blueprint, by the current ASX guidelines and by the Equal Opportunity in the Workplace guidelines, which are now setting targets for women to be involved. Where I'm looking at that, I'm not saying a woman with disabilities has to be on the board, but I am saying, "Please look at that." We won't necessarily have people with disabilities as those boards, although I'm hoping as well that you will look at disability representation at all levels of governance.

I'm asking if you please could look at those guidelines that are currently operational. I think that as well I would like in the final report to see more employment commitment built in for people for disabilities. I see those opportunities at all levels in the scheme: that not only will it be catering for support services for people with disabilities but at all levels there be opportunities for people with disabilities, and naturally we would want women with disabilities to be employed in the scheme, and we would like that to be able to be built into the final structure; that there would be positive discrimination for women on the governance levels, those high levels; that there' be positive discrimination for employment of people with disabilities throughout the scheme.

My last point that I'd like to make is on when we're looking at the complaints mechanisms and whether it's separated. We don't have an opinion on that, but where we are thinking that women with disabilities do require assistance is in actually getting into the complaint system, where advocacy, and individual advocacy, would assist them to make their complaint and to raise awareness that complaints could be made, that they don't have to stoically endure something with which they're not pleased or which is not suiting their needs, and to walk them through that system. I think it would be good if in the final report we could see some mechanism for assisting people to develop those skills to be able to advocate for themselves eventually, but some advocacy assistance be available.

MS SCOTT: Thank you for that. We have got some material in there about the disability service organisations and the regional people also playing a role. Thank you for those comments. John, do you have any questions for Sue?

MR WALSH: Sue, I remember you brought up the issue about the imbalance between the ABS survey and the receipt of support. We'll have a look at that. From memory, I thought it was because the age distributions were different. So that would skew the result.

MS SALTHOUSE (WWDA):   There certainly are some bubbles, and I think we talked about that as well, where there is more young men coming through. I think we look at the SDAC for 2009 the initial figures show that in the nought to 15 age group there in fact twice as many boys as girls and one of my concerns there is that there has been much greater diagnosis of autism spectrum disorders which seem to be a little bit a sex-linked condition. So what we would be looking for in the implementation phase is to make sure that other conditions at any particular age group don't get drowned out by predominance of one particular diagnosis. But I note and thank you for your emphasis in the draft report on the needs basis that when that's more promoted and begins to permeate our system that I can see better outcomes for women.

MS SCOTT: Thanks for coming along, Sue. Thank you.

MS SALTHOUSE (WWDA): Thank you.

MS SCOTT: Welcome to the table Nick Parmeter and Bill Redpath from the Law Council of Australia, please. Welcome and good morning. Would you like to identify yourself for transcript purposes and make an opening statement, please. We've allocated 30 minutes for your presentation, but do anticipate questions. Thank you.

MR REDPATH (LCA): Thank you for that. My name is Bill Redpath.

MR PARMETER (LCA): My name is Nick Parmeter. We're both here on behalf of the Law Council.

MR REDPATH (LCA): We certainly don't intend to speak for half an hour and happy to answer questions. Thank you to the Productivity Commission for the opportunity to appear and provide further views on your interim report. We agree with the assessment that there needs to be increased funding in the disability area. We agree with that analysis that it's under-resourced, that services and access to them are patch and that there is a lack of coordination of those services. We support in principle the National Disability Insurance Scheme as outlined and we believe it should be comprehensive in terms of its care and support and that it needs to be well funded.

We take a perhaps a more pragmatic view to the Productivity Commission in the sense that we regrettably don't see that we're currently in an environment where there is much attraction for big ideas, grand schemes in government and we take, on that basis, a pragmatic view that the priority ought to be getting the NDIS in place and we say that because we say the priority is to get to those who fall between the cracks who do not appear to be covered by other schemes as a priority and we say, as the most saleable of priorities in terms of persuading the powers that be, that this could and should happen. We say that in terms of the disability resources that those, for example, that are covered by statutory schemes such as workers compensation do have already some greater access to these kind of care services, to a variety of health services and that the priority ought to be, in establishing the NDIS, getting to those who fall between the gaps in the schemes as well as obviously providing an injection of services that could be accessed both by those in the NDIS scheme and those in other schemes.

Clearly if there is more money in the disability sector, it's likely that disabled workers, those disabled in motor vehicle accidents would also be able to access them irrespective of that. We say that the NDIS should not be the priority of the Productivity Commission and we say that because there are difficulties in simply getting some kind of scheme such as that up. We speak from perhaps bitter practical experience in the difficulties of getting all of the jurisdictions to agree on a national legal profession, the difficulties of the jurisdictions in agreeing on national OH and

S. As the Commonwealth do not have, with it's own bailiwick, an area where people are catastrophically injured that isn't the ACT, New South Wales, Victoria, et cetera you would simply be creating a bureaucracy to do things whereas the powers reside with the states.

Our view is that you should recommend, although not have a NDIS, that you should be recommending that the various jurisdictions establish greater no-fault arrangements, particularly where none exist for catastrophic injuries and accidents. I think in our original submission we indicated that we supported the extension of those sorts of schemes in jurisdictions that don't have them already and I think the recommendation should be, from the Productivity Commission to the states and territories, that this should happen. An expansion of and those schemes in the various jurisdictions is the first step and then we can look at something perhaps like an NDIS to coordinate it. But at this stage there aren't sufficient schemes and there isn't sufficient will in the state and territory governments to do that and I think it would be a real shame if the NDIS, as a scheme, ended up being shelved or not taken seriously simply because of those difficulties.

At least the advantage with the NDIS, we say from a practical point of view, is that we only have to persuade the Commonwealth which is, we accept, a big ask but nevertheless we only have to persuade one area of government that they ought to be embarking on this and that in fact, at least in the short term, the NDIS would pick up aspects of the catastrophically injured so that they would be covered. The question then for us is the interaction of the NDIS with existing schemes as we don't think in the foreseeable future those are going to be altered and we say that a model which allows people to opt in or opt out is an appropriate one so that those people have a choice and then it's a question if they're entitled - and if they're covered by a scheme already such as they would meet the criteria but they're getting those benefits under, say, a workers compensation scheme, then they wouldn't be part of this scheme, they would continue to get those benefits. It would be only where they were not getting a benefit under that scheme for whatever reason that they would then access the NDIS.

In circumstances where they accessed the NDIS but ended up with a lump sum compensation, there are various models that we can deal with that. Those three types of models are the model in the HOSC Act I guess what Medicare do which is to require a notification and those moneys are paid back out of any settlement; the Centrelink model which is somewhat different because there is payback for incapacity but also a preclusion period model as a result of an assessment of damages and perhaps we say an alternative model would be a payback and perhaps buy-in model where people could, if they got a lump sum, choose to access the services either under the tier 2 scheme simply as a referral service or for there to be mechanism for them to use their damages to buy into the scheme. Anyway, those are things that we think would make it more practical.

I guess we don't share the Productivity Commission's view in relation to common law entitlements and their benefits. We say probably in relation to that given that our view is that the NDIS should proceed as the priority, we probably don't have to resolve our differences and persuade you that the common law is very good, as you do not need to persuade us about your views about it in the sense that the NDIS can and should stand alone from the current statutory entitlements and the Productivity Commission has dealt with their view about what should happen at common law in the workplace. In a sense it's a red herring to the more important work of establishing the NDIS.

So we take that view and we comment in relation to the discussion of common law that we are surprised by the tone in chapters 15 and 16 in relation to the legal profession. As far as I can tell the legal profession, for all its ills, have not caused any great number of people to become significantly disabled and thus contributed directly to this problem and I'm not quite sure why we get the treatment we do in chapters 15 and 16. But we say that in passing and we put that aside in the hope that we might constructively engage in the debate about the NDIS.

In terms of our concerns with the NDIS scheme itself, one of those is the very limited rights of advocacy within the scheme that, unlike even Centrelink entitlements, there are independent merit based forms of review available to the Centrelink beneficiaries in terms of the SSAT and the AAT. In the Victorian scheme there is also a capacity to appeal to VCAT in relation to decisions. The experience, we say, in relation to internal review is not marvellous. From my own experience in relation to Comcare there is an interview review mechanism and I think that's a useful mechanism but it would change about 20 per cent or less of the decisions. The Administrative Appeal Tribunal then changes another 50-odd of those decisions and so that as an independent mechanism that is good.

It seems to me that disabled people clearly do have particular problems and that their access to this scheme which is of benefit to them ought not to be the cost of their rights to advocacy in relation to problems with the scheme. That particularly becomes the case in terms of if, for example, as is proposed there are various models for care. We would be unhappy in a situation where, as a result of the scientific modelling, it was decided that people who had cerebral palsy were entitled to one hour of massage a week, one hour of hydrotherapy a week because that's the standard and that everyone would get some kind of standard and would not be able to advocate their differences and be advocated in a situation where they get some form of independent review.

I guess as a profession I know that the legal profession is criticised for the situation where we're alleged to be judging ourselves. It seems to me that's exactly the model here and that that's undesirable. We think that there are relatively cheap mechanisms that allow independent review and that are adopted in those schemes and we would prefer you to go down the route of, say, the Victorian scheme then the New South Wales catastrophic scheme which doesn't have those kinds of review rights.

Our only other concern is the costs of the scheme and our concern, although we concede that we're not economists or accountants or actuaries, that the costs of this scheme, even the NDIS aspect may well be significant greater than estimated. We say, for example, in 2010 the New South Wales Lifetime Care and Support scheme has total care and support expenses around $38 million for a scheme that covers just 390 people, with a pool of around four million Australians who may be eligible, we are concerned about there being those costs.

MS SCOTT: Do you think that's a good point of comparison?

MR REDPATH (LCA):   I think it's just an indicator that the costs of dealing with disabled people, particularly severely disabled people, are very significant and we believe that it's a project that is worth pursuing. We simply indicate our caution in relation to it and the importance of saying to the government, to the public, "This scheme, if it is run properly, to be fully funded will cost this money and we'd say it's an important scheme that we as Australians should be supporting." But I don't think we're doing any favour to the scheme in saying, "It will only cost X." We would like to see further costs. That's our concern, we need to make it clear up-front to those people who we wish to adopt the scheme that that will be the cost. Otherwise the experience, I suppose, is that you end up getting a situation where you start with certain benefits and they simply get pared back in order to cover the scheme costs and that is the usual panic about, "Well, this scheme doesn't have these reserves. The scheme doesn't have this money. We have to pare back everyone's entitlements." We simply raise this as having seen that cry so often.

MS SCOTT: I just wonder whether the validity of that point of comparison - the commission is very interested in doing more costing work and I think we have indicated that in the draft and we look forward to commentary from all participants about any suggestions for improvements in costing methodology because it's a very difficult area. But I've just wondered whether that comparison that you've suggested stands up to scrutiny. Anyway, you might wish to - - -

MR REDPATH (LCA):   We put it merely as being illustrative of the potentially high costs of the care functions of such schemes.

MR PARMETER (LCA):   I think the point is that there aren't really many points of comparison for a scheme of this nature in relation to severely and profoundly disabled people or catastrophically injured people. So this is a model which is held as perhaps an indicative example of what a catastrophic injury scheme costs in relation to a certain number of people.

MS SCOTT: But the four million isn't actually the number of people with catastrophic injuries. I just think the point is - - -

MR PARMETER (LCA): No, we understand that.

MR REDPATH (LCA): We should put on the Productivity Commission's report actually refers to about 355,000 people who may be eligible for the NDIS and then - - -

MS SCOTT: Tier 3.

MR REDPATH (LCA): That's right, tier 3 of the NDIS and then additionally there may be some discretion to provide entry to more. So really the comparison is made not with the four million with the 355,000 and we're happy to provide you with a copy of our opening statement which sets that out more clearly.

MS SCOTT: I'd welcome getting that. Nick, do you wish to make any further comments?

MR PARMETER (LCA): No, I think the points have been well made. In relation to advocacy, I think a further point that should be made is that removal of rights to appeal on the merits in relation to a scheme is a particular concern and it's something which removes an important incentive, the authority to establish what might be regarded as robust dispute resolution mechanisms within the scheme; that is, the Law Council understands that under the Victorian TAC scheme, for instance, there are very strong dispute resolution mechanisms which have been developed by the commission. Really those have arisen as a result of the commission's desire to avoid appeals processes that result from decisions made by the commission.

MS SCOTT: Thank you. John, do you have some questions for the Law Council of Australia?

MR WALSH: No, look, I think that was pretty clear. Thanks, Bill, thanks Nick, for that.

MS SCOTT: I think I'll look forward to getting your submissions. Thank you for coming along today.

MR REDPATH (LCA): Thank you.

MS SCOTT: We now have Mark Blumer from the Australian Lawyers Alliance, please. Good morning.

MR BLUMER (ALA): Good morning.

MS SCOTT: Mark, could you just identify yourself for the transcript, please. We've assigned 30 minutes for your presentation, again depending upon whether we ask questions whether we'll need that time. If you would start.

MR BLUMER (ALA): My name is Mark Blumer. I'm the president of the ACT branch of Australian Lawyers Alliance, and the immediate past president of the national organisation.

MS SCOTT: Would you like to proceed now.

MR BLUMER (ALA): Okay. The ALA, which is the Australian Lawyers Alliance, welcomes increased funding and improved services for people with a disability. The ALA considers a single scheme, that is the NDIS, is desirable and warranted. The ALA questions the need for the creation and implementation of the dual system of an NDIS and NIIS. This would appear to create, at the very least, the potential for a duplication and for increased costs. The ALA says that appropriate levels of funding must be committed to the scheme. It should not be permitted to bring a lowest common denominator approach to the provision of services to those with a disability.

There must be sufficient and properly qualified staff available across Australia. In addition, we say that it is essential that any scheme enshrines a right to care philosophy. The presumption of a need for the requested care should be built into law; in other words, the onus of proof should be on the decision-maker if they wish to decide that a person does not need requested care. This would help to address the current power imbalance in all schemes between the person requiring care and the decision-maker. It is also essential that any scheme allows for an independent right of review to an appropriately qualified body so that the principles of natural justice are not extinguished.

It is not appropriate, we say, to have the review within the sphere of influence of the decision-maker. The person should be entitled to legal representation, independent medical expertise and should not face the threat of adverse costs orders and should be entitled to recover their own costs if successful in that mechanism. An appropriate forum might be the Commonwealth Administrative Appeals Tribunal. The ALA opposes the removal of existing legal rights for persons injured through the negligence of others to seek redress through the common law system. The ALA sees the capacity for an NDIS to complement existing rights.

The emphasis should be on assisting those who cannot access one of the existing schemes and not removing existing rights of people. A person involved in a common law claim should be able to access services within the NDIS framework during the course of their litigation and then refund to the scheme in a similar way as occurs with Medibank, Medicare and Centrelink and as recommended at page 1641 of the draft report. This would prevent delay in accessing care for those with common law rights - a very serious problem.

We believe that the draft report's current focus on dismantling a scheme that works fairly well, we would say, to replace it nationally with an unfunded, no faults scheme, threatens the ability of the nation to properly introduce the much needed NDIS. But, of course, the commission knows what the Australian Lawyers Alliance believes. That doesn't seem to have changed much recently. ALA now knows what the commission believes. Perhaps that hasn't changed much either, despite this inquiry.

In slightly simplified form, what we learn from chapters 15 and 16 is fault based systems are bad; no fault schemes are good; injured people fritter their money away and then expect the taxpayer to look after them; claiming compensation is bad for your health and delays recovery; lawyers are so greedy that removing them from the process would almost completely fund the new scheme, and so incompetent that removing them would also speed the process considerably. The desire for justice is really just a primitive desire for revenge. The fear of being sued for negligent behaviour has little or no effect on behaviour. Courts and judges are irrational; bureaucrats are rational and can predict the future better than judges. Bureaucrats know better than disabled people what care they need.

What we have to ask about these things we learn from the draft report is what weight they should be given. That will be a matter for the Commonwealth government when they receive the commission's final report. In my view, the evidence in favour of the proposition that has so far been accepted by the commission is at least patchy. Most of it has never been rigorously examined or tested. Much of it is anecdotal. Much of it is really based on, "Well, everybody knows that" - just fill in the end of the sentence.

This is a difficult subject, the intricacies of which are hidden from most of us, including me, because the research has not been done. The controversy that has been generated by Spearing and Connolly's study - is compensation bad for health - is symptomatic. Both sides of that controversy at least agree on one thing, that more primary research is needed. The research needs to be done rigorously and extensively before these important public policy decisions are based on what we think we know.

Perhaps we are now not much further on than New Zealand was when they introduced their no faults scheme in 1974. Geoffrey Palmer, initially a great champion of that scheme, five years later said, "The argument against the common law in the 1976 royal commission was largely based on principle." There was almost no empirical data in New Zealand on who got what, when and how from the common law system. Only modest amounts of information were collected by the royal commission itself.

20 years later the same person then, Sir Geoffrey Palmer, described the New Zealand scheme as, "Now more in the nature of a mean workers compensation scheme which covers injuries for 24 hours a day." A mean workers compensation scheme model is not what anybody wants. I think we surely agree on that. I suggest that the commission's approach, or that part set out in chapters 15 and 16, should be reconsidered.

MS SCOTT: John, do you have any questions for Mr Blumer?

MR WALSH: A couple, Mark. Thanks for that. I agree with you that more primary research needs to be done. One of my commentaries on the nature of common law based schemes is that even 25 years after the introduction of the Woodhouse reports we have not been able to collect any more information or data on what actually happens to people. That's a major issue. I think it's great that the ALA is suggesting that we do more primary research on that in that area. My second point is around one of the very early things that you said, which is that under the NDIS the onus of proof should be on the NDIS to question what someone claims is their need, and in claiming that need and in arguing that truth the person with a disability would be entitled to legal representation. Is that right?

MR BLUMER (ALA): That's the second step. There are two steps. The first step is that it should be enshrined in the law that, prima facie, the person asking for care is correct in their request. So that then the decision-maker needs to say, "No, because" - blah blah blah, and give reasons. In other words, rather than the person who needs care having to muster the evidence - and apart from the obvious primary evidence, that is, "The doctor says I need this," or whatever - it should be up to the decision-maker, who has got much more facility to do so, to say, "No, you don't need that, because of this." Then if that goes to a review - there should be an internal dispute mechanism probably, like in Centrelink or the Social Security Tribunal, but then after that, if there is an independent review, with the AAT or someone else, then they should be entitled to legal representation at that point.

MR WALSH: So that system would effectively enshrine a no-fault entitlement based on a claim for anyone with a disability?

MR BLUMER (ALA): Yes, I think so. I think that would get rid of a lot of the concerns that people who act for injured people, or injured people themselves, would have.

MR WALSH: That might as it unfolded be almost like a common law environment for disability entitlements

MR BLUMER (ALA): I don't think so - well, except it's not a once-off type situation. It's not a lump sum situation, it's ongoing care.

MR WALSH: Yes. Okay, but apart from that, that's how it would unfold. You might have disputes on a regular basis every couple of years maybe when the person's care needs changed.

MR BLUMER (ALA): I don't know. I don't work closely enough with disabled people in their ongoing care needs to be able to comment on that. I very much doubt it, and the Human Rights Acts have shown the same thing, in the UK and in Victoria and in the ACT, what happens is the decision-maker's behaviour has changed. First of all, prima facie, they have got to make a decision based on evidence and so forth, instead of whatever else; and secondly, because there is a dispute mechanism, that backs into the decision-making.

That's how the Human Rights Acts have worked, whereas it was talked about that it would create litigation and work the lawyers, blah blah blah. The same thing is being levelled at us here; that is, "Oh, you're just trying to make for yourself," Well, I don't think that's correct. I know it's not correct, because I know that sort of work, if it's on the basis of making more money, it is not remuneratively rich work. So I think that society has to take some of what we say as lawyers without a kilogram of salt; some of it, not all of it.

MR WALSH: Thanks. That's useful.

MS SCOTT: Mark, do you have a view on one of the key questions that we ask in the overview - which is about the issue of the dividing line between mental health services and disability services?

MR BLUMER (ALA): No. No, I don't have a view on that. But what do you mean?

MS SCOTT: Well, one of the issues that we pose is that people with severe psychotic conditions may find that they have troubles with some of the daily functional needs that we are likely to see with people with intellectual disabilities, or people sometimes with physical disabilities, say, sensory disabilities; and on the other hand, these people have clinical needs and often have associations with the mental health sector, sometimes they don't even see themselves as having a disability but having a mental health issue, so perceptions are important. I'm just interested in your views about where you consider there should be the appropriate delineation between the two systems.

MR BLUMER (ALA): I don't know about that. But what do know is that people with severe mental health difficulties, which can last for a very short period of time, need access to high levels of care and they should not be excluded from an NDIS or any of the facilities that could be provided by an NDIS on the basis that it's not long-term enough. I do have experience in those sorts of situation, and it is most important that that sort of care is available.

MS SCOTT: Thank you. Any further questions for Mark, John?

MR WALSH: No. Thank you, Mark.

MR BLUMER (ALA): Thanks, John. Thanks, commissioner.

MS SCOTT: I think we will now adjourn for lunch, and we'll resume at 1.45. Thank you.

(Luncheon adjournment)

MS SCOTT: Good afternoon. We recommence our hearings. Welcome to the table, Anne, who is representing herself. Anne, we have allowed 25 minutes for your presentation.

MS CAHILL LAMBERT: Let's hope I can do it faster than that, I might say.

MS SCOTT: We'll see how we go.

MS CAHILL LAMBERT: I'm sure you'll both easily understand the problems. Thanks for allowing me to appear personally and thanks to your staff for making the arrangements so that I could do this. I get out of bed for three reasons each day: the first is the free oxygen for all Australians who need it, and that would be everyone; the second is for improved organ donation rates; and the third is for decent coffee and wine by the lake. So I'm here for the first today, just making sure I haven't confused them. I have read your plain English report. When I became ill I sharpened my focus and just decided to read what I really had to. So if there's any detail that I haven't understood, I'm sorry about that.

I want to really be sure that you've got the oxygen issue right as far as aids and appliances are concerned in your report, and I don't know whether you had thought about oxygen or not. I find that lots of people don't, in relation in relation to disability. But it is a major problem. Some years ago - Ms Scott you might remember this, having been here - I had a public argument with governments generally and health insurers as well about access to oxygen when I became ill. I was gobsmacked about how little was provided to patients, and in fact it's means-tested for most patients in Australia. You need to have a Health Care Card, and, as you know, that's a pretty tight restriction, yet oxygen is quite expensive.

Here in the ACT I was lucky enough to be able to convince our government to provide oxygen for patients who need it, on an uncapped basis, but no other government in Australia does this. I am often approached by patients around Australia and I listen to the saddest stories on earth of patients; you know, they might be asset-rich because they own a farm out at Dubbo, or a cherry plantation or whatever, and they sell off bits of their farm so they can buy oxygen, and then they worry about how much money they're going to have left for their family or how many assets for their wife, or husband, and children as a result of that.

Let me be clear. The only way you can afford to buy oxygen in this country is if you're a gazillionaire. Whether you're married to someone incredibly important or what, who might seemingly have a lot of money or not, oxygen is really expensive. I think problems have occurred in the provision of oxygen in this country for two reasons. Firstly, for the muddling of Commonwealth and state and territory arrangements, in relation to the health sector in particular; you know, there are things, as we know, that fall into that great big, black chasm, and oxygen seems to be one of those.

Then the second issue is value judgments I think seem to be made. Now, that's a big call, I don't have evidence to say that, but it's my feeling that that's the case. I should declare here I have a rare lung disease, it's called fibrosing alveolitis. I'm a lifetime non-smoker, but I often have people come up to me and say that I deserve everything I get, because I've smoked. I think people assume when you're on oxygen that you've smoked and you deserve to pay for whatever it is. However, even if people have smoked, I still don't think we should be making that distinction. We don't do that in relation to dialysis. We don't do it in relation to people who go and play on football fields against people who are twice their height and weight and everything else. We don't do it for mental illness. We don't do it for other chronic illnesses. We don't do it for AIDS. Why would be do this for people who have a chronic lung condition?

In other sectors of the health system we don't expect people to bear the cost or the burden of their disease in the way we do for oxygen. So people who are on oxygen who have lung disease bear the bulk of the costs. Some jurisdictions, and even mine up to a point, say that you can have enough bottled oxygen - so you can have a big oxygen concentrator - I don't know if you know the technology around oxygen - whether you do, Mr Walsh, as well - but there's these big machines that plug into the wall, they're like the 1970s air-conditioners, they're very noisy, very heavy, most people get those, although some don't, and it costs $70-odd to hire them a month. Then if you're very special, then you can get some bottled oxygen, to just go and see your doctor. So you can't go and shop, you can't go on holidays, you can't do anything really.

I find it odd that in this health system people are not able to participate in the ordinary endeavours of life. I also find it odd that most health systems across Australia do have as one of their mantras the idea that, "Even if you have a disability, we want to firstly keep you out of hospital, keep you well enough to participate in life, to not be a burden on society or your family," yet with oxygen we find that that's not the case. It is an expensive commodity because no-one has bothered to review the technology, other than me.

In fact about three years ago I imported a portable oxygen concentrator, which makes me independent, and I'm fierce about my independence. Even though I'm married to the best-looking bloke in Canberra, nevertheless, I do some volunteer gigs, I'm on various committees and so forth, and I want to be able to go and do those things without him. Most people do want to be able to be as independent as they possibly can, yet they can't do that unless they have something portable.

I would also say to you if you're worried about the cost, remember that once you go on oxygen it's a slippery slide to hell, mostly you die fairly quickly, apparently other than me - I'm a burden on the government and everyone else just because I'm stubborn. I get out of bed every day because I've figured out that staying in bed kills you. Most people do die in bed. But people don't tend to live a long life once they go on oxygen. The major burden of disease in this country probably is to do with smoking. If you have emphysema and you need oxygen, then you are really near the end.

I don't know whether you have seen many people in shopping centres, at the movies, on aeroplanes, on holidays on oxygen. I'm willing to bet you haven't. You don't see us out and about. That's because we're all at home stuck, tied up to our oxygen machine, making our families miserable, making ourselves miserable. The issue, of course, is that the money for oxygen comes out of a different bucket from the mental health bucket, from your family not being able to go to work bucket, from you not being able to go to work bucket and so forth. So we're not able to bring all of those things together.

Now, I'm no health economist but some years ago I did write a paper - given that this is one of my three aims in life, and you are my last chance, let me tell you and this is my last point. So I did write a paper and I worked out it would cost us $30 million to stump up for free oxygen for those Australians who need it. So there is a capital outlay of that and then there is a running cost of about one and a half million a year. If you're worried about where that money might come from - and I'll give you that submission if you want me to, I'd don't whether it's too late to do that. I'm just an ordinary housewife from Lyneham. I've got nothing special, no particular skills. But I just did a guess. We don't actually have a register of who's on oxygen and who is not but I just did this guesstimate and came up with that number.

I read yesterday that defence is going to save us $100 million on some boat they're buying. Let's take $30 million out of that. Or, of course, smokes are in the news this week. Of course, there's a truckload of tax on cigarette smoking and that might be another way of funding it. But I guess I would urge you both to consider that oxygen is part of your brief, an important component of it. That's all I had to say to you.

MS SCOTT: Thank you very much. Clearly you're underselling your exposure to the health sector from a variety of fronts, including your professional exposure which I note on your paper was considerable. I have one question for Anne, John, if I might proceed. Is that all right?

MR WALSH: Yes.

MS SCOTT: Anne, you talk about considerable personal costs involved and I think in your submission to us you refer to the fact that you've had to use up a fair bit of your own superannuation.

MS CAHILL LAMBERT: I've used all my superannuation. The disease I have, diagnosis to death is five years and I'm just over that. I'm hoping to break all the statistical evidence, if you like. But I envisaged not living a long life so it didn't matter in the end.

MS SCOTT: You keep talking about the considerable cost but what is the cost? Can you give us some sense of how much you've spent on it. I don't care what point of reference you want to use.

MS CAHILL LAMBERT: The point of reference is that - the oxygen machine at home, there's a monthly cost to that.

MS SCOTT: You said $70.

MS CAHILL LAMBERT: Yes, it's 70-odd at the moment. Then oxygen bottles, it just depends on who's selling them and what size you have. I think the ones I had were about $30 a pop. I was going through eight or nine a day. You've got to breathe and I'm on four litres a minutes. These machines go up to five litres a minute. So I'm high-end user. To have a lung transplant you need to be - it's a hoot - fit and healthy. So I go out and ride my bike or I go walking and you use more oxygen if you're doing that. I'm sure if I sat at home and just read and didn't talk - an issue that has never been tested in my life, I might say - I'd probably use less. So 24, 40 - it just depended how I was going and what I was doing each week. In one year I spent $30,000 on it.

MS SCOTT: Wow. Thank you very much. John, some questions for Anne?

MR WALSH: It would be useful to get that … on the number of people and the cost, that would be useful. Do any of the equipment and aid schemes provide oxygen, that you're aware of, around Australia?

MS CAHILL LAMBERT: Well, the ACT does and that's as a result of my big public fight or a caring government in the end that realised it was foolhardy not to do it. Queensland and New South Wales are the worse governments - it's easier for me to do it that way - because I think Queensland still you have to be on a lung transplant list to get any support. New South Wales, they did use the healthcare concession card as a rule but once their budget is blown for each area, then there is no money left so you have to buy it yourself. Then they make rules if you live out in the bush then you might need an emergency cylinder or something like that, so they might give you once or two of those. But by and large - - -

MR WALSH: PADP scheme.

MS CAHILL LAMBERT: Yes, so it's all under the PADP schemes or - yes, that's exactly right. That's where it sits but there's just not enough money for oxygen.

MR WALSH: Thank you.

MS SCOTT: You make a strong case for this but if you do you have any further information about the costings, we would appreciate that but also some of those little short case studies about the fact that funding runs out within the PADP program would be quite useful.

MS CAHILL LAMBERT: I can pass those on. It is difficult because - of course, I don't want to criticise but, here I am, I'm about to - governments don't want to admit that they don't provide oxygen. This is the most basic of all requirements. In New South Wales I think I am considered a serial pest in that jurisdiction. I sent you a copy of a letter I had written to Dr Kelly.

MS SCOTT: Yes, I've read it.

MS CAHILL LAMBERT: You should see the response I got from federal health who are well meaning. But they haven't sat back and thought, "If this was me or my mum or my child, how would I feel?" The letter that I got back from the department was four pages long, "So for the patient's diabetes they should go and do this. Sorry, oxygen is a state matter, so they should go and do that. For their mental illness they should go and do something else." So there is no way of bringing all of this together and let me tell you, if you're on oxygen because you smoked - I mean, it's bad enough for me and I'm reasonably assertive. I feel bad enough that I'm a drain on the economy and not in full-time work and not doing anything particularly useful.

But if you have smoked, imagine the guilt in all of that and that you are this drain on your family and so forth. You're not going to admit it to people, you're not going to try and get help and so forth. So it really is a horrible, horrible life. I've sat around outpatient clinics looking at incredibly sad and miserable people who are just waiting for death basically.

MS SCOTT: John, anything more?

MR WALSH: Thank you, Anne.

MS SCOTT: Thank you for your submission and coming in today.

MS CAHILL LAMBERT: Thanks for having me.

MS SCOTT: I next call to the table Mary Durkin, please. Thank you very much for coming along. Just for the transcript, because we're making a public recording of your testimony and it will be up on our web site later, could you just identify yourselves for the transcript and then over to you for an opening statement and then we might ask a few questions. We have about 25 minutes for your presentation.

MS DURKIN (DCS): My name is Mary Durkin and I'm Disability and Community Services Commissioner here in the ACT and with me is my senior disability adviser, Kelly Swan.

MS SCOTT: Thank you.

MS DURKIN (DCS): Thanks very much for giving me the opportunity to come and speak with you today about the inquiry. I just thought I'd briefly outline my role. In my role as commissioner one of my responsibilities is to make recommendations to government and non-government agencies on legislation, policies, practices and services that affect people with a disability and their carers. I also promote improvements in the provision of services to people with a disability and I also deal with complaints about services in the ACT for people with disabilities and their carers.

I must say at the outset I haven't yet made a submission to the inquiry. I haven't yet formed a view on all the issues in the report. I'm still talking with people in the sector here in the ACT. So my main reason for coming along today is to comment on the aspects of the report that relate to complaints and oversight mechanism because I do have some thoughts about that. But just up-front I'd like to state that I welcome the idea of a national scheme that seeks to provide long-term care and support for eligible people on an entitlement basis. In my role I am familiar with the local disability services system and I agree that in many ways it is fragmented and insufficient to meet the level of need in the community. In my view reform of the disability services sector is definitely overdue and I welcome the work of the Productivity Commission in creating a blueprint to assist in guiding this much needed change.

In terms of general concerns about the proposed scheme, I have a few points. I have a number of concerns raised with me by others in the disability sector here in the ACT. I agree with the sentiments that have been expressed by others that the scheme needs to engage a social model of disability. I believe it is critical that any assessment of a person with a disability should seek to assess the supports that are necessary for them to achieve full participation in society and to provide funding in accordance with that objective rather than looking predominantly at care needs attached to an individual's disability. I think particularly in this context that it will be critical to consider the consistency of assessments and the qualifications and experience of assessors.

I have heard echoes of concern regarding the potential harshness of assessments and while I recognise the need for prudence in managing a complex yet finite scheme, it is vital that people with genuine and eligible need are not assessed out of the scheme, so to speak, or provided with less than optimal supports. I will develop my thoughts further on these aspects of the scheme in finalising a submission to the commission.

But the main reason being here today as the person responsible for oversight and resolution of complaints about services for people with a disability and their carers in the ACT, I have an obvious interest in the proposals that relate to complaints and dispute resolution. The reasons for departing from a standard administrative law approach of providing independent merits review of decisions made under legislation that affect a person's interests and of independent oversight in relation to service provision are, to my mind, not convincing. The proposal to locate oversight mechanisms within the NDIA itself, even with an independent statutory appointment will still raise concerns about potential bias and importantly, the public's perception of a lack of independence.

The one-stop shop approach of placing everything within the NDIA is also likely to raise issues of conflict of interest on a number of fronts. Arguments that the complaints office should be located within the NDIA because of the expertise required are also not compelling. The expertise developed in the Social Security Appeals Tribunal, for example, provides a relevant comparison. While acknowledging that the NDIS wouldn't have an unlimited supply of funding, it's essential that the decisions made by NDIS staff and contractors are open to scrutiny and are fair and transparent.

I believe that the NDIA should be subject to the standard suite of administrative law options, internal review, independent merits review - I would suggest by a specialist division of the AAT, perhaps the SSAT itself - ombudsman oversight of the NDIA's administration and the ability to appeal to the courts on matters of law. Concerns that merits review would result in unsustainable threats to the scheme can be addressed through setting clear legislatively parameters are decisions to be made and the approach to be taken. To remove the right to seek merits review of funding decisions that will so significantly impact on people's lives would treat people with disabilities inequitably in comparison to other citizens. It may also be discriminatory when it's established practice in other fields to provide merits review of individual funding decisions, for example, compensation decisions or taxation decisions, vets affairs decisions and so on.

Oversight of disability support organisations and disability service providers requires a different approach to the approach of reviewing decisions made by the

NDIA. Whilst it's noted that the intention of the NDIS is to empower people with a disability to become customers who will move their business elsewhere if displeased, the reality is that making such a move would be a significant and disrupting decision and people will not make those decisions lightly. We all know that we grumble about our banks and our telecommunications providers and so on but people don't simply just move to other service providers when they have one or even two complaints. They might do so after months or years of frustration but they don't make such a move easily.

People dealing with service providers require flexible and informal complaint resolution processes to deal with day-to-day issues that arise. An appropriate oversight body should have investigative powers, mediation and/or conciliation functions, powers to compel the production of documents or to interview people, referral powers and recommendatory powers. In the event that service providers fail to comply with recommendations made by the oversight body, further recommendations might be made to the NDIA to address the issues with the service. As flagged in the report, these might include things like sanctions or potentially removing an organisation's certification and thus its funding.

As a network of bodies already exist in the states and territories for oversight of service provision, it would make sense to continue using these bodies to undertake this role. They have a wealth of experience in resolving complaints about service provision in the local level and have extensive corporate knowledge about the quality of the service providers in their jurisdictions. They have existing relationships with people with disabilities in their jurisdictions and people do not have to continue telling their story over and over to them.

These bodies are variously disability service commissioners Victoria and the ACT, ombudsman offices Tasmania and New South Wales, and combinations of health, disability, community services commissioners in Western Australia, South Australia and the Northern Territory. Only Queensland would require an independent local presence. A nationally consistent approach can be achieved through working with these bodies to develop common approaches and parameters for reporting back to the NDIA.

I believe it's absolutely critical that an effective and strong scheme has in place an impartial, professional and defensible process for the investigation and resolution of complaints. I hope I have provided some food for thought in this area and we welcome any questions.

MS SCOTT: Thank you. John, would you like to start off.

MR WALSH: I have a couple of questions, Mary. You seem to imply that any misunderstanding around entitlements or processes could be handled by making it clear in the legislation what those were. We would appreciate any advice on how you would do that and some places where that has been effective in an area like this, where the entitlement will be an assessment of services. My second question relates to the idea that the existing commissioners in the various jurisdictions should continue as they are. We have heard from virtually all the jurisdictions that that's broken. So what you say about the fact that the service providers are well known and the people with disability are well known to the commissioners seems to raise questions around how successful those commissioners have been in reconciling problems in those jurisdictions. So I would appreciate your comments on those points.

MS DURKIN (DCS):   Sure. I've spoken with all commissioners in the other jurisdiction or ombudsmen et cetera and they all concur with my view but I appreciate that you're saying that it's others that are saying that it's not working. I think there are different approaches being taken in some of the organisations. Clearly in the Victoria and New South Wales we've got a specific designated disability services commissioner and I think having that title and role increases your visibility and your acceptance by the community. If the commissioners are within ombudsman officers or health services commissioner officers, then people don't necessarily appreciate that they're there and automatically go to them. So it may be that basically having the title of commissioner is important is in terms of visibility of what commissioners can do.

My main point is having an external oversight body rather than within the NDIA that is able to do the sorts of things that we do under our legislation is our main point. I would defend how we operate here in the ACT to the hilt. So, yes, there certainly may be room for improvement around the country. I suppose it's just maybe that I don't think an internal complaints handling body is the way to go. I have another hat of being health services commissioner and I often have people say to me, "Well, you know, of course I wouldn't go to the medical board, would I? They're not going to be independent." So even if you set up something within the NDIA and say it's independent, people won't perceive it's independent, is my main problem.

In relation to your other question I might do a little more research around that issue. I think assessing someone for a bundle of entitlements should be no different than assessing someone for an income in terms of what your review rights should be. So when someone is making a decision that impacts on your rights and your entitlements, I still think there should be independent merits review of such decisions. But I'll go back and have a look at - - -

MR WALSH: When you're doing your research you might bear in mind that assessing someone for an entitlement to income is a binary decision, it's off or on. You either get the income or you don't. In this system there's a question of quantum.

So you might get $500 a week, you might get $5000 a week. The merits review will be around deciding whereabouts on that scale someone might fit. I just can't conceive in my mind how you would establish that in legislation.

MS DURKIN (DCS): Okay. I'll have a further think about that.

MS SCOTT: One thing: in the report itself it talks about ways that if there were to be a merits review of decisions these are some of the ways you can put parameters around it, and I didn't disagree with those. I guess my continuing concern is at the end of the day how you ensure sustainability because you effectively can't bind a judicial position or sustainability in an arrangement along the lines you've suggested. At least that's the advice we've received. I wouldn't mind going on a different tangent in relation to your suggestion that we should have as our principle a full participation in society rather than on the basis of needs.

I think you used the word "care" needs, but I think we're probably a bit more comfortable with "supports". But full participation in society is clearly a desirable goal but given that the last speaker was talking about something as fundamental as oxygen supply and that many states and territories do not provide services that she outlined, and I think you heard her testimony and you're probably very familiar with her lobbying.

I just wonder how realistic it is to imagine that a scheme could move from such a highly rationed arrangement as we have now, with clear inadequacies in every jurisdiction, to one that's based on full participation. If you think that what we've outlined is inadequate and it costs 6.3 billion, do you have a notion, Mary, of what a full participation model might cost?

MS DURKIN (DCS): No, I certainly haven't tried to do that sort of exercise. I appreciate it probably would represent quite a significant increase in the amount of money that would need to go into the system, but I basically think that if we're going to be a country that complies with the human rights of its people that has ratified the United Nations Convention on the rights of people with disabilities which include the right to full access to the community, the right to have a family life, all the sorts of rights that we expect as people who do not have disabilities, then I think we've got to find a way to try and maximise our adherence to that protocol.

MS SWAN (DCS): Yes, absolutely. I think it was Nicole Lawder from the Deafness Forum was speaking to you at an earlier point in the public hearing and talking about the needs of people who have hearing assistance or use Auslan and interpreters and those sorts of things, and the ways in which potentially they might be not assessed with such seriousness as other types of supports as people who have more typically profound disabilities, but how critical something like that can be for that individual's ability to work, to participate, to contribute to society, to have a social life, to access the community in an adequate way.

So I guess that was one of the catalysts for our thinking about, how does it become a broader focus and not just a focus on the needs of people with the most typical, high, profound support needs, if that makes sense.

MS SCOTT: A little, though as you know our eligibility criteria goes beyond that.

MS SWAN (DCS): Yes.

MS SCOTT: For your own jurisdiction, Mary, have you done any work on how far the current arrangements in the ACT are from the full participation in society outcome?

MS DURKIN (DCS): As I said at the start, I think the current arrangements in the ACT, like everywhere else, are fragmented. Sometimes people are getting very good supports, particularly if they have ISPs that are well managed. A lot of people are just missing out. So it's certainly not consistent in the ACT. There have been some good efforts at being flexible and innovative in providing funding to enable participation in society, but it's certainly not across the board that people have access.

MS SCOTT: But the extent of the divergence between desirable level of outcome and current position?

MS DURKIN (DCS): I haven't done any assessment of that. Basically we're a very small office. The majority of our time is in dealing with individual complaints, and our ability to undertake other activities outside of complaint handling is very limited.

MS SCOTT: Okay. In your submission, I wonder if you would feel comfortable commenting on the costs estimations we've made on complaints as well. We'd welcome your input on that.

MS DURKIN (DCS): Yes.

MS SCOTT: John, any further questions from Mary and Kelly?

MR WALSH: Mary, I'd also be interested in your submission if you could derive whatever information you can, without breaching confidentiality, of the number and types of complaints that you get.

MS DURKIN (DCS): Sure. Some of the complaints we just mentioned - we get complaints about people's personal care needs: if a carer doesn't arrive on time, someone might not get a shower, might lay in a wet bed for hours; or someone is rough when they get showered; people's accessibility to the community; transport might not be appropriate for the type of wheelchair that they've got; or people arrive late and people don't get to appointments on time. It's across the gamut of the sorts of things that you would expect in people's daily lives.

MS SWAN (DCS): There's also issues around the availability of both genders of carers. We do hear quite a bit about that when people have strong preferences for men versus women, and services' ability to deliver on that. Numbers of staffing required: some people are requesting two individuals for certain types of transfers and lifts and elements of their personal care, and that's not able to be delivered. Anything from mismatched expectations around what a quality service should look like and what the individual is expecting to receive.

Communication between staff and the recipients of those services, as well as to the management level of services. There's just difficulties in communication across the board. We get such a wide raft of complaints really, and it's anything from something that seems quite manageable and that somebody wouldn't automatically jump up and pick a new service, versus things that are quite major and require huge systemic - sort of looking at all elements of the service.

MR WALSH: We've had most of those stories presented to us but I don't think we've got it in a, "Here's 12 months' worth of complaints from a per capita population." That would be useful.

MS SWAN (DCS): Sure.

MS DURKIN (DCS): In our jurisdiction we've got about 40 complaints on our books at the moment. I would say we've probably had about 50 or so this year to date, but we can certainly do an analysis of them for you.

MS SCOTT: Does your remit also go to the non-existence or non-availability of service in terms of the existence of a waiting list?

MS DURKIN (DCS): Yes.

MS SCOTT: Well, we'd be interested if there's a way to get the breakdown on those complaints, you know, how many relate to a service being available but a waiting list existing versus the number of people who are concerned about the gender of a carer - that would be quite useful.

MS DURKIN (DCS): Yes.

MS SCOTT: Mary, I'd be interested in your view on the Office of the Public Advocate in some jurisdictions versus your sort of function. I'm just conscious that in Victoria this seems to be the role of the public advocate, particularly to handle complaints on restrictive controls on individuals in the disability sector and so on. Is that a function you perform here in the ACT as well?

MS DURKIN (DCS): No. Basically we're set up to be independent and impartial. We're not advocates.

MS SCOTT: No, I said the Office of the Public Advocate.

MS DURKIN (DCS): Yes, and so the public advocate will do advocacy for people in relation to issues, but then she will refer systemic matters to me if she considers that they need to be looked into.

MS SCOTT: Okay.

MS DURKIN (DCS): But, yes, we're very much independent. The public advocate has a different role here.

MS SCOTT: So people can make complaints direct to you, or do they have to go to the Office of the Public Advocate?

MS DURKIN (DCS): No, direct to me.

MS SCOTT: So if someone had a concern about restrictive practices in an accommodation setting here in Canberra, they would be made directly to you?

MS DURKIN (DCS): Yes. We have had that type of complaint in the past.

MS SCOTT: Thank you. John, I have exhausted my questions.

MR WALSH: Yes. Thanks very much.

MS SCOTT: We welcome getting your submission, and just remind you gently that it's 30 April if you'd like to - - -

MR WALSH: Indeed.

MS SCOTT: Thank you for coming along.

MS SCOTT: I now call to the table Liz Ruck, please. Thank you for coming along. For the purpose of the transcript, could you state your name please and your organisation, and then would you like to go ahead and make an opening statement. We have allowed just on 25 minutes for your time.

MS RUCK (MHCA): Okay. That's good. I'm Liz Ruck from the Mental Health Council of Australia. The Mental Health Council is the peak body for nongovernment mental health organisations in Australia. That's not organisations necessarily from the NGO sector, it also covers organisations like the AMA, colleges of medicine, that sort of thing. We haven't actually finished consulting on our final submission yet, but it was important to come here to make a few initial points I thought and just give some background. The National Mental Health Consumer and Carer Forum, with whom we work at the council - we actually auspiced that organisation - they're going to be doing a submission as well, which could be very useful.

Psychosocial disability is the term that mental health consumers and carers use to describe the disability experience of people with impairments and participation limitations that are the results of mental health conditions. The principles around psychosocial disability are the same as for any disability, and psychosocial disability is covered by the UN Convention on the Rights of Persons with Disabilities, to which Australia is a signatory. The Mental Health Council welcomes the inclusion of people with psychosocial disability in the National Disability Insurance Scheme heartily.

The effects of psychosocial disability can be severe and the impact is frequently underestimated for both people with the disability and for their carers. Research into psychosocial disability and its effects and ways to reduce its impact has lagged behind policy development and research in comparison to other areas of disability. The statement that the National Mental Health Consumer and Carer Forum are putting together in response to this inquiry is a statement defining psychosocial disability. That will be really useful in the mental health sector as well as for people outside the sector.

As with other disabilities, people with psychosocial disability and their carers require a range of supports to assist them to participate effectively in the community. There's a significant lack of those sorts of supports in the community, adequately specialised or trained disability services to address the disability support needs of people with psychosocial disabilities. Generic disability support services don't always have the skills and knowledge to understand and identify and meet the support needs of people with psychosocial disability or their carers. Many are not aware that people with psychosocial disability need their support services, and I think the draft report acknowledges that.

Many government departments providing support services to people with psychosocial disability don't have the skills or knowledge to identify and meet those needs, such as departments of housing or Centrelink. So the failure to adequately identify psychosocial disability and provide appropriate community supports for people in Australia has resulted in extreme social isolation, exacerbation of mental health conditions, poor labour force participation, increases in physical health conditions, resulting in pressure on acute health services and community health services, not to mention the undue hardship and poor quality of life experienced by mental health consumers and carers.

Australia's social inclusion agenda needs to be developed more appropriately to reflect a community of socially-excluded people, because we believe that this community includes a significant proportion of people with psychosocial disability. In the UK the social inclusion agenda recognises that people with mental health conditions represent significant proportions of that socially-excluded community. Australia's social inclusion agenda does mention people with psychosocial disability - or, people with mental illness, they say - but really only in relation to employment, and there's significant area for improvement in the way that agenda is written out and the sort of initiatives that come under it. The council thinks that the overhaul of Australia's disability system represents an opportunity to address that.

The effects of disability, if not addressed, can exacerbate mental health conditions, causing hardship for mental health consumers and carers and an added demand for health and disability services. Addressing support needs for people with psychosocial disability requires a consideration of the needs of both consumers and carers, I can't emphasise that too much; carers are often left out, particularly when psychosocial disability is concerned. I am not an expert in other disabilities. I'm not an expert in psychosocial disability. But carers really need to be considered; they play a huge part in the lives of many people with psychosocial disability.

I guess I wanted to say that people with psychosocial disability are not some stereotypical, hospital based, illness-inflicted people, they're actually people like us in the community, like any person with a disability. They may become intermittently ill and some of them may have ongoing illness that's not controlled or symptoms that are not controlled, but they still require disability supports. The issue of psychosocial disability - or psychiatric disability, as it's commonly called; mental health consumers and carers prefer the term "psychosocial disability," they think it more effectively describes what they're going through - because it hasn't been well explored and identified, means that assessments of people with psychosocial disability are poorly done.

Mental health assessments of people with psychosocial disability are not designed to identify disability support needs, and mental health services are not funded to provide supports to people with psychosocial disability, we wanted to emphasise that. Traditional and mainstream assessments of people with a disability can often fail to identify the most disabling aspects, again because it's not a well-explored area. For example, Centrelink job capacity assessments, there's always real problems with those. You're obviously familiar with that.

The Productivity Commission report is fantastic, but it doesn't adequately identify people with psychosocial disability, and I think the report recognises that. It's possible that the commission does have the data that could assist in identifying it, but it doesn't come out in the report. The use of severe and profound core activity limitation data is used to identify people with psychosocial disability, and that's really problematic. Core activity limitation measures those core activities - communication, mobility and self-care - and psychosocial disability may or may not be picked up in an assessment of those three areas, a person may well be considered to be completely functional in those three areas: able to feed, cook for themselves, catch public transport, make themselves understood in public.

But they may have all sorts of other impairments, which means that they will dress inappropriately in public, they'll isolate themselves socially, they won't want to communicate with people, they will find it difficult to hold down a job and they won't necessarily be able to maintain their own home, very much like people with intellectual disability. I'm not saying they are like people with an intellectual disability, but those impairments have the same sorts of results. I think the Productivity Commission recognises that severe and profound core activity limitation doesn't pick up everyone with an intellectual disability, and as a result they have made provision for that in the identification of people who are going to be participating in the scheme.

So they have made a range of recommendations about who might participate in the scheme and they have also said people with intellectual disability have got their own kind of separate dot point or line, because they realise those people may not be picked up by severe and profound core activity limitation. So they say that this is because people with intellectual disability may not be necessarily restricted in core activities but may still require assistance with non-core activities, such as catching public transport. It's those kinds of non-core activities areas that can be really disabling, and are severely disabling for people with psychosocial disability. So we would strongly recommend that the commission considers the inclusion of people with psychosocial disability in its data-collection processes, if possible.

I realise there probably isn't much else collected except severe and profound core activity limitation, and if we're using that as a proxy then we need to really identify who are the people that are going to be and going to be out. The commission has said that they have made some provision for people with psychosocial disability, which is fantastic, but, given the number of people with profound core activity limitations and severe core activity limitations with mental illness that have been identified, it's not clear which ones of those will be used by the commission and what sort of provisions they're going to make for the fact that that doesn't necessarily pick people up who are severely disabled by their psychosocial disability.

The other thing I wanted to talk about is the questions that the Productivity Commission ask about the mental health sector, and they are seeking feedback on where the boundaries between the mental health sector and the National Disability Insurance Scheme might lie. The commission suggests that the boundaries between the roles of disability and mental health sectors are blurred for the most severe and enduring mental illness, and we would argue that this isn't the case, and I will go on to talk about that.

The other thing that the commission suggests is that the mental health system is under review. If it was, that would be great; but it's not, as far as we know. The mental health sector has been lobbying in a major way for a long time. You would be aware about problems with the health sector and what people with psychosocial disability and mental illness need. There have been numerous reports about the sorts of needs that people with mental illness have. If you read through those reports, a lot of those issues - accommodation, employment, social inclusion - are all disability issues.

The minister for mental health has gone around the country talking to people about what might happen in the mental health sector, but that certainly doesn't constitute a review, and he hasn't made any promises about what he is going to be doing. given the fact that he has got numerous reports already outlining the sorts of things that need to happen. Some people are cynical about what those consultations might mean. We don't think it's a done deal that the mental health sector is going to get a big bunch of disability supports in the next budget. They might get some health-specific input, and that is sorely needed as well, but that is different from disability supports.

The essence of disability support - and I probably don't need to tell you this - is that it's not about being illness or clinically based but it focuses on individual capabilities and support needs and it locates people in their homes and the communities, not in hospitals and health centres. It would be really inappropriate for the health system to be providing social inclusion supports for people with physical disabilities or intellectual disabilities, it doesn't happen, and it should be the case for people with psychosocial disabilities.

I think this is one of the battles that the disability sector has already fought and made some gains in. The psychosocial disability sector is in its infancy and still fighting. The roles are very distinct. The disability sector is best placed to provide disability support. The health sector is best placed to provide health services, and does so for people with disabilities daily for all conditions. There's a requirement for coordination between the two. It is the same for people with psychosocial disability as it is for people with profound disabilities who require regular interventions from the health system.

The commission has asked which services would be provided by the disability insurance scheme and not the mental health sector, and I think it has given a really good example in its report about what those sort of things should be: that the mental health sector would be responsible for specialised services and things that they're experts in, like psychology, psychiatry, early intervention in health and psychiatry, acute and inpatient services and pharmaceuticals for all types of mental illness.

The commission has gone on to say that provision for all services for people with nonpermanent mental illnesses, such as many affective disorders, would also be provided by the mental health sector. What I'm saying that those specialist health services should be provided by the health system and disability services should be provided by the disability sector, for reasons that I have previously outlined. On the issue of nonpermanent mental illnesses and many affective disorders, many of those people would have psychosocial disabilities as well, particularly people with affective disorders, and they may come under the remit of the National Disability Insurance Scheme. Does that make sense?

MS SCOTT: I think we'd probably want to explore that.

MS RUCK (MHCA): Okay, yes.

MS SCOTT: I think I have understood what you said though.

MS RUCK (MHCA): The commission goes on to say that NDIS would have a significant role in meeting the support needs of individuals with dual diagnoses such as those with intellectual disability and mental illness, and I would say other dual diagnoses; disabilities from mental illness and drug and alcohol problems, their disability needs still exist. You look very sceptical. I guess we'll talk about that. Cost shifting, of course it wouldn't be the role of the disability system to prop up a failing health system, no-one is suggesting that. We wouldn't want that, in fact. Funding should be located squarely in the disability sector. There is already an established community-managed - what they call mental health sector, that is actually providing disability support services; a very small one, and it's crying out for more development and more funding.

The way to stop cost shifting I think is that the health sector has already a history of not being able to provide community based supports. Sure, it's providing some of those small ones but compared to the health budget it's a tiny amount.

Those things are generally focused on prevention and early intervention but the health system, as we know, is struggling to prioritise funds away from the hospital and the acute sector, something that the Health and Hospitals Reform Commission put in a major report about and suggested major reforms around that haven't really been taken up. The mental health sector would be very concerned if disability supports were being provided in the health sector. We don't think the funding would be prioritised appropriately. We think the idea of an MOU between the health system and disability services is a great idea. It's needed now. It would also help the coordination issues that those services may have.

The small amount of disability support that is being undertaken in the community managed mental health sector, they are actually exploring opportunities for having those kind of MOU arrangements, identifying who has carriage for what and those are working fairly well, I think. I could give you examples of those in New South Wales and Victoria if you're interested. That is probably all I need to say at the moment.

MS SCOTT: Thanks, Liz. John, do you want to lead off?

MR WALSH: Liz, I think you've done a good job in demonstrating to us how complicated this is.

MS RUCK (MHCA): I thought that was simple.

MR WALSH: We have, as I'm sure you'll understand, a lot of difficulties with us. You mentioned that there are community mental health facilities and - - -

MS RUCK (MHCA): They're not facilities necessarily, there are community mental health services.

MS SCOTT: Services.

MS RUCK (MHCA): It's an important point.

MR WALSH: They're currently funded out of the health system?

MS RUCK (MHCA): Some of them are.

MR WALSH: Where are the others funded from?

MS RUCK (MHCA): They're sort of funded by a mishmash of state and territory and Commonwealth funding. Things like the personal helpers and mentors program which is firmly located in the community is funded by the Commonwealth Department of Families and Communities Services. Something called Day-to-Day

Living which is day-to-day living support for people with severe mental illness is funded by Commonwealth Department of Health. There are other reports that outline the different - and it depends on how the states and territories arrange their funding. Some disability supports come under health and some don't. So it depends what state you're in and I think the commission outlined that in the report.

People with psychosocial disability can also access generic disability support services but I think I said those services are often not well set up to provide supports to people with psychosocial disability and certainly the data on the CTSDA, Commonwealth State Disability Agreement disability services shows that a very small proportion of people with mental health conditions is accessing those services compared to the number of people that we can identify who may have severe and profound core activity limitations.

MR WALSH: I think for the most part those people with psychosocial disabilities who are currently supported by the disability system are usually at a level of support that we have already recognised that would be covered by the NDIS. The issue for us is that I don't agree with you that all sorts of disability have daily contact with the health system. Most types of disability have very rare contact with the health system and don't have a clear continuum of care that involves the health system such as the mental health area does, so I think that is a fundamental issue.

MS RUCK (MHCA): Wouldn't someone with MS or arthritis or - - -

MR WALSH: There are rare occasions that have regular but not the same sorts of contact. Someone with MS is more likely to have a physical disability attendant care type program rather than a regular health program.

MS RUCK (MHCA): Right. They don't go to the doctor for colds or flu or anything like that?

MR WALSH: I've got quadriplegia and I go to the doctor for colds, the same as anyone else in the community does.

MS RUCK (MHCA): Yes, I can see that that is slightly different. Sorry, go on.

MR WALSH: So I think there is a difference between mental health and other types of disability.

MS RUCK (MHCA): But is that an issue?

MR WALSH: I think its links with the health system is an issue. The funding coming from health at the moment is an issue for us. I also have a question around, is the mental health sector uniformly agreed that they want to be in the NDIS?

There have been many efforts over the years to distinguish mental illness and psychiatric disability from intellectual disability. “We're not like that. We don't have an intellectual disability.” So I just want to be clear [whether] everyone with a mental illness wants to go in this way.

MS RUCK (MHCA): I haven't consulted everyone with a mental illness and I don't know if anyone has. But what I'm saying is that the Mental Health Council of Australia is proposing - its members are saying that. I understand your point about intellectual disability but I think that's a different point. Trying to distinguish between the two sorts of disability is very different to trying to access support for being under the same scheme. I think people in the mental health sector have actually been working on putting the NDIS, working with the Australian Federation of Disability Organisations really strongly to be part of the scheme. They think it's a fabulous idea and would welcome the idea of personalised support services that are directed by people with disabilities and they think that is perfect for people with psychosocial disabilities.

MR WALSH: Okay, thank you. It's a difficult area.

MS RUCK (MHCA): Okay.

MR WALSH: I have no more questions, Patricia.

MS SCOTT: I appreciate that you outlined right at the start, Liz, that people are working on this definition of psychosocial disability now. But I might go back to what was provided in August to us in a submission from the National Mental Health and Consumer Carer Forum and in a footnote to that submission it said:

> There is tension in both the mental health and disability sectors around the most appropriate language to describe persistent mental illness or psychosocial disability. For the purpose of this paper psychosocial disability is primarily used, although where people with mental illness or mental health consumer is used, it should be taken to read as some with psychosocial disability related to persistent mental illness.

I guess a couple of points to take out of that was the reference to "persistent" quite clearly a couple of times.

MS RUCK (MHCA): Yes.

MS SCOTT: We know that a very large number of Australians have all sorts of disabilities - if I take my glasses off you start blurring up on me - but with the use of fairly readily available aids or assistance or support or counselling can find that they don't have a persistent impairment. We're on the same wavelength?

MS RUCK (MHCA): Yes.

MS SCOTT: So while a large number of Australians identify as having a disability, in terms of the individualised packages, you could see in the draft report we did effectively narrow it to four groups. I guess what you're trying to do - quite reasonably from your perspective - is draw connections between the definitions we've used and how groups within the psychosocial sector could be perceived. I just want to draw that out a bit more.

MS RUCK (MHCA): Yes.

MS SCOTT: If it turns out we go over a little bit of time, that will be all right. I will make sure that the other speakers still get their allotted time. So please don't get anxious, audience. Let's just take it a little bit further. In the draft report we struggled with where to draw the boundary lines and we spent quite bit of time in the text saying, "There is considerable uncertainty here. There are reasons why there are strong ongoing connections between people with mental illness who have regular, episodic connections to the mental health sector." John is drawing that distinction in his last example to you.

MS RUCK (MHCA): Yes. Sorry, John, I did sort of understand that.

MS SCOTT: Then we said on the basis of core functional needs, functional limitations, it may be the case that there are groups within certain severe psychiatric conditions that may actually have a set of core needs that are not too dissimilar to people with physical or intellectual disabilities. We drew that group as a small group. I think what you're effectively seeking to convince us this afternoon is that that group should be much larger and that we should see that the rationale for the inclusion of people with intellectual disabilities should be the same argument that is used for this wider group of people to be. Is that a fair summation of your position?

MS RUCK (MHCA): It is, except that we don't really have much idea about how big the group is.

MS SCOTT: Right, okay.

MS RUCK (MHCA): That was the point I was trying to make.

MS SCOTT: That goes to the heart of the issue and that goes to the issues that we've said. So while there is a little bit of uncertainty - well, there is considerable uncertainty, I should say in our mind about where to draw the line - and that's why we're very keen to hear from people like your organisation. If you're suggesting that we draw the line somewhere else it is pretty important that we know where to draw it and what the numbers are.

MS RUCK (MHCA): Yes.

MS SCOTT: In your earlier submission it's clear that there was some recognition that it was persistent mental illness. So we know that people with some depressive disorders can, without counselling and with therapies, overcome their illness, it's not a permanent condition.

MS RUCK (MHCA): Yes.

MS SCOTT: It's true that there can be people who have high-level needs - if you end up with a broken leg, you can high high-level needs for a very short period of time but it will, with good treatment, disappear. But that's not the same as a person with a permanent disability. I just wonder whether - - -

MS RUCK (MHCA): Sorry, I beg to differ.

MS SCOTT: All right, okay. Because otherwise if your argument is that it doesn't need to be persistent, that it can be episodic, it can be short term, then that argument on the short-term basis could be used for someone with a broken leg and a broken arm.

MS RUCK (MHCA): Sure, yes.

MS SCOTT: So is the scheme going to include everyone with a broken leg, a broken arm?

MS RUCK (MHCA): No.

MS SCOTT: Right, okay. I can you just tell me about why - - -

MS RUCK (MHCA): Why we put persistent mental illness in - - -

MS SCOTT: If you have persistent mental illness in August, I guess I'm a bit curious that you didn't mention persistent mental illness in your submission today.

MS RUCK (MHCA): To be very frank, disability and mental illness is something that has always - we've got so many needs in the health sector that creating relationships with the disability sector with FaHCSIA, getting the Department of Health to try and talk to FaHCSIA - they are supposedly talking to each other anyway under a whole of government approach but it's obviously not happening - has been something that's way down on the priority list for mental health and the

Mental Health Council. When the disability support scheme started to happen we found out about it. A few weeks before those submissions were due in we thought, "We have to be involved in this." We put a - I don't want to say it was unthought about - it was probably an undeveloped view, we thought severe and persistent mental illness would typify what we were talking about when we were talking about psychosocial disability. I think that's wrong and it's been misleading to people outside the sector.

I think people within the sector would understand what we were trying to do but outside the sector not and you can see from the Productivity Commission's report not many people put in information about psychosocial disability and the differences around it. We weren't the only ones who didn't have a developed view on this. It's something that needs to be done in the sector is this sort of conversation and this was the opportunity to do it.

Since that time the Mental Health Consumer and Carer Forum we've got them involved and they've said, "Look, this is psychosocial disability. What are you talking about? We need to do something about it. Quick get together the literature on psychosocial disability." We went away and tried to do a literature review and there isn't any, you know, internationally there isn't any. So they thought, "We'd better write some," hence the position statement. It has unearthed a lot of not very well thought out ideas in the mental health sector about what we might be talking about as well.

MS SCOTT: Okay. Where we were with the issues paper - just to explain a bit more - was that our terms of reference had used this for "a severe and profound" based on the ABS definitions that we were increasingly becoming uncomfortable with.

MS RUCK (MHCA): Yes.

MS SCOTT: DIG had done all the earlier work to point to very difficult interface issues about who is in and who is out in that earlier work on something like an insurance model. So then we used the phrase "those most in need". So even if you have trouble with the eligibility criteria that we have developed and you're asking us effectively to extend it further, as far as I can tell from today, to basically to everyone with a mental illness - - -

MS RUCK (MHCA): No, not at all.

MS SCOTT: Okay. So what - - -

MS RUCK (MHCA): I'm sorry, and I haven't had a chance, I guess, to tell you what I think is psychosocial disability.

MS SCOTT: No, okay. I guess what I want to know is, if it's not everyone with a mental illness and it's certainly broader than what we have in the draft report, could you tell me what it does extend to?

MS RUCK (MHCA): It's people who have a mental illness who have a resulting psychosocial disability. So who have impairments as a result of their mental illness that are ongoing past the episodes of mental illness and there may well be - we haven't defined it but there may well be some arbitrary point at which it needs to be defined to limit it. That, you know, if a person has a psychosocial disability for more than - someone can have a severe acute psychosis and have a traumatic experience in the mental health sector and it can last for three years and they might not be diagnosed - I'm just making up an example - and they miss out on schooling, they're homeless for that period of time.

They've suddenly got all these disabilities as a result of that situation. They're isolated, they have cognitive difficulties as a result of their mental health condition being left untreated for so long. They've finally managed to come into contact with the health and have their illness controlled. They have cognitive difficulties as a result of the medication that they're on. They're severely socially isolated, they don't know how to function in the community and they've come out of an institution and they don't know how to wash or dress themselves and have never been taught how to do that. Those sorts of things are disabilities.

MS SCOTT: Okay.

MS RUCK (MHCA): Does that make sense or is that still too nebulous?

MS SCOTT: This narrows it a little bit, so I welcome the greater definition.

MS RUCK (MHCA): That will certainly be in our submission.

MS SCOTT: The challenge that we have goes back to the central purpose of our task which was to assess the feasibility of a proposal. The broader and broader and broader the number of people - - -

MS RUCK (MHCA): Sure, I understand.

MS SCOTT: - - - to which assistance has to be provided, to be frank, the less feasible it becomes. I know you didn't say this, but earlier today we had someone say that effectively the disability and the aged care sector need to merge. Well, think about how many more millions of people that would take into account. So I guess at every point we have to have some discipline a clear rationale for any extension and the questions we asked - I guess we're after the most disciplined answers in answering those things. What services exist out there, what services - even if they don't exist now - - -

MS RUCK (MHCA): What services do you want?

MS SCOTT: You may well want them but the question that has to arise is whether they're best within the disability service sector or best met in two other sectors that are often referred to in relation to mental health and that's one called the mental health sector and the other one is called the community sector. Anyway, I think we've all got our work cut out but we look forward to getting your submission and maybe I should wrap it up there, Liz.

MS RUCK (MHCA): Okay.

MS SCOTT: John, any further questions?

MR WALSH: Any further clarification on what support needs we think we're talking about and any information on how many people you think there are would really be useful, Liz.

MS RUCK (MHCA): Yes.

MS SCOTT: Sorry, Liz, I have one other question. The COAG last communique referred to the fact that mental health reform would be under consideration at COAG. So I just want to check, if you're not aware of any review going on, do you know what they're going to be considering at the next COAG meeting?

MS RUCK (MHCA): No.

MS SCOTT: Okay.

MS RUCK (MHCA): They have a couple of the ministerial advisory council advising them.

MS SCOTT: All right, that's fine. Thank you very much.

MS RUCK (MHCA): I was going to say something more, John, but I can't remember what it was. I'll try and put it in our fabulously descriptive submission.

MS SCOTT: Thank you.

MS RUCK (MHCA): Thanks.

MS SCOTT: Welcome to the table Dr Ken Baker from National Disability Services, please. Good afternoon, Ken.

DR BAKER (NDS): Good afternoon.

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

DR BAKER (NDS): Thank you and thanks for the opportunity to meet at this public hearing. NDS, as you know, represents non-government disability services and we have around 700 organisations across Australia we represent. We're currently consulting with those organisations in relation to the draft report on disability and so the issues that I will discuss today are preliminary views and we will provide a full submission by the end of April.

I do want to say at the outset that I and NDS find the draft report enormously impressive in its scope, in its depth and its significance. It's probably unrivalled, I think, certainly in my time in the disability sector in those respects. So although we will - and today I'd like to identify some areas that I think need to be clarified are changed, these are principally areas of detail. The main architecture I think is pretty compelling. So the issues that I have listed in the submission or the points I'll go through today are - the first relates to the place of employment, disability employment services. I think the report is not consistent on this so I think some post-draft report says that all specialist disability services will be included within the NDIS but at other places it's not clear.

I think in terms of the estimate of the eligible population I don't see how that estimate that 360,000 can encompass the full population of people who currently receive services through a specialist disability employment service which is funded under the National Disability Agreement. Secondly, there are two points in relation to the eligibility criteria. The first relates to the inclusion of intellectual disability. I think the reasoning of the commission in including people with intellectual disability is sound. That is, there are some people who would not qualify as having a core activity limitation but do have great difficulty forming and maintaining relationships and those relationships are critical to their social and economic participation. But in defining that group as a condition, intellectual disability, rather than as a functional need, I think the commission has excluded groups with comparable need like some people with acquired brain injury, some people with autism. People, in other words, with other forms of or other causes of cognitive impairment who would experience just the same difficulty forming and maintaining relationships.

The second issue in terms of eligibility relates to the early intervention group and I certainly applaud the recognition of early intervention, the importance of early intervention in preventing the escalation of need. I guess what I'm proposing here is not stretching the boundaries very, very far but recognising that there are people - that because in the scheme put forward there is a very big jump between tier 2 and tier 3, tier 2 being access to information and referral only, then I think there needs to be some accommodation of people who may have a permanent disability, an ongoing disability but only require occasional or periodic support and it may be just provision or renewal of expensive equipment. Maybe you're thinking they will be accommodated but I suppose that's a point I just wanted to emphasise.

The report puts a strong emphasis on market, on the operation of the market and it has a strong focus on individualisation. In general we would support the strong focus on individual choice and we recognise the environment you're envisaging is one where there is more competition. But I think there is too little attention given to the importance of community building within this. It's very difficult, I think, within the funding model you've put forward to envisage how that community-building function which is very important, particularly important in the context of the national disability strategy, how those benefits or that need can be attached to individuals through individualised funding packages. I think there needs to be some other stream of funding that makes sure that - it's often local communities, these are not national campaigns, that local communities are more accommodating, more receptive, more supportive of people with disability.

There is also, I think, a need within the efficient price that the National Disability Insurance Agency would set - there needs to be some recognition of not just capital maintenance but capital growth. There are waiting lists in every state and territory for group homes - it's not clear how they would be funded through this scheme - and for maintenance of infrastructure. The final point relates to minimum qualifications. The draft report makes a blanket recommendation that there should be no minimum qualifications mandated, it will be up to individual organisations as to the qualifications they insist on and then my reading of it is that customer choice, market choice will sort out how important that is to consumers.

I think that blanket statement is going too far. Without going into detail now NDS has put - it was a contentious issue in the disability sector, we consulted extensively about it and we've come up with, I think, a view that there should e a minimum induction program for all staff. There is an opt-out provision. We have put forward for people who are directly employing someone for a specific unskilled support function but in general we think there ought to be some minimum, at least induction program, and not to have that risks. I think risks are diminishing the quality of services and deskilling a fairly low-skilled sector.

MS SCOTT: Thank you, Ken. How long would the minimum induction program go for?

DR BAKER (NDS): It would be something that would have to commence within the first six months of employment and then could take, you know, another six months but not done as anything full-time. But it would include elements like occupational health and safety, first aid, knowledge of the disability service standards and then it would be the first building block, I think. So it would consistent of competencies which would fit within the national framework so it could become the first building blocks to a formal qualification.

MS SCOTT: John.

MR WALSH: Thanks, Ken. They're all helpful points. I've got a couple questions and comments, I guess. All of your points will be taken down and we'll have a look, I think. One about a big jump between tier 2 and tier 3 and the need for community building, capacity building and I think this also involves the issue of the market and the market is not just going to appear, the market needs to be built and cultivated. I would be interested in any idea you might have on what that would take in terms of quantum of funds. I think we can do a little bit more in the report about that but what we sort of implicitly expected is that the slow roll-out period would allow some margin of funds to be available to play that build-up role. Any idea you've got on putting some bones around that sort of process would be very valuable in how you would go about capacity building. It also goes to your point about worker induction and what sorts of things might help that.

One of the things that has come up in one or two of the hearings around the place is as disability and health and aged care also become bigger parts of the economy the notion of support workers or care workers disability workers are likely to become more viable career options. So the idea of those being even advertised in schools has been mentioned to us. So any sort of creative ideas like that that NDS or some of its members might have would be useful.

My other point is around your issue of the cost of capital.   Off the top of my head I think it's around 8 per cent of the highest category of support which comes to around $400 million a year. I guess our notion had been that even though that's a flat number, it's an annual number, the notion of investment by business and depreciation of that amount would effectively mean that you could get a much bigger infrastructure than that capital amount up-front, so any comments you've got on that would be useful as well.

DR BAKER (NDS):   Okay. Just to be clear on the last point, you're saying within your figures at present $400 million per annum for capital?

MS SCOTT: Supported accommodation and so on.

DR BAKER (NDS):   Okay.

MR WALSH: That's right.

MS SCOTT: We could probably be more explicit in the final report.

DR BAKER (NDS): That would be good.

MS SCOTT: It certainly was our intention that it's in there. You'll see it in chapter 4 but you might not have seen a heading on it in terms of some of the other chapters.

DR BAKER (NDS): There are a few points. In terms of the workforce, I think as you've recognised in a recruiting, retaining and I think training the workforce is going to be a big challenge because it is quite a shift in culture, I think, that you're proposing. It is a positive move but it's quite a shift in culture which does require a different skill set and probably a more complex skill set, more autonomy on the part of support workers. So I think that emphasises probably the importance of having at least some mandatory induction process. In terms of recruitment the most successful thing that is happening in Australia at present is Care Careers in New South Wales. That is a comprehensive strategy to recruit and retain staff. The most visible elements of it are television advertisements, but it has a lot of back office to it enabling profiling career pathways and people testing their orientation to the sector, linking with jobs and so on.

It's worth having a hard look at it and it has, I think, an important by-product in that you've seen the advertisements, and the advertisements can be viewed on the Care Careers web site. They are advertisements that are not just targeted at recruiting support workers but as it happens - because we found it the most effective way of doing this - it actually shifts the public view about what having a disability means. So when we began developing this campaign we found that the public view of disability support work was quite outmoded. People didn't appreciate that the most attractive part of disability support work is assisting people to achieve their goals. So the stories that the advertisements tell and the web site tells are stories of people with disability having aspirations and achieving those aspirations with assistance.

MR WALSH: Thank you.

MS SCOTT: Can I seek your view on the issue of the boundary lines with mental health. I think you heard some of the conversation with the last participant. Could you share your view on the right boundary lines.

DR BAKER (NDS): I think that for people with mental health problems there is frequently a need for significant involvement with the health system in terms of their medication and dealing with acute episodes. But the disability perspective comes into play where people have not acute but ongoing support. Living in the community with significant restrictions to their participation or their functionality because of an ongoing mental health issue. So where there is community service support required, I guess that is where they interact with disability support services. It is, as you would appreciate, a growing proportion of the disability support pension population and it's also a growing proportion of people - psychiatric disability is a growing presence within particularly the population of people who receive disability employment services.

MS SCOTT: In terms of membership of your organisation, could you give us figures on the number of organisations that would probably identify themselves as mental health organisations that are part of your organisational structure?

DR BAKER (NDS): There would be a small number who would see themselves as principally mental health organisations. There would be a larger number who found themselves at the interface between, for example, intellectual disability and mental health because of people having dual conditions and there are, in addition to that, some specialist providers within the disability employment service system that identify their expertise as being principally in the area of mental health. It's not a large number though.

MS SCOTT: In terms of community building, a number of consultations have highlighted the role that community organisations or even individuals within often a suburb or a town can mean to the quality of life of an individual and the involvement of people. John, I'm discussions Clinton and I had with people at Walgett and some of the discussions we had with people at Moree, a very strong community sense in some of those places. There wasn't a government person standing there or even an NGO in some cases standing facilitating that, there already was a community spirit.

We had one organisation present to us in recent days with the view that one of the downsides of having a well-funded, needs based model was in fact that it would reduce the need for fundraising and fundraising was a way that you generated community involvement. So I guess what I'm interested in asking you is how do you see community building occurring? Why do you think there is a need for a government catalyst? If you do think it necessary, when do you think that government catalyst is necessary and can't we just leave it to communities to do this? There are lots of organisations like Lions and Rotary and so on. Or do you agree with the participant we heard from that said that one of the downsides of any idea that was about well-funded schemes was that we wouldn't have community participation?

DR BAKER (NDS): Look, I suppose at the margins there is a risk that a scheme that entitles people to services can encase them in those services and cut them off from the community. I know that is not the intention of this scheme and I think that is why I would envisage this proposal of an NDIS as part of the national disability strategy which has a strong emphasis on making generic institutions more responsive to people with disability. In some cases this occurs spontaneously, there are examples of that and they should be applauded but I most cases it hasn't happened like that. We're, in Australia today, an affluent country where people with disability, as your inquiry found, are still grossly disadvantaged. Natural supports, if you like, are vastly overstretched.

So I think that nature of disability service provision is shifting and there is a much stronger orientation today toward not in simply providing passive consumers with support, but assisting people to participate in their surrounding lives. There is quite a skill involved in doing that well so that it is done in an unobtrusive way but a lot of those skills do in fact exist within the specialist disability services system and they take time and they take effort so ultimately they need to be funded.

Just to underline the point the government's big vision - and I'm talking about governments collectively around Australia of the national disability strategy endorsed now by COAG - is of a much more inclusive society where people with disability are being encouraged to participate in all domains of life. But there is recognition within that strategy that there is a very, very long way to go and if we just allow it to happen by natural evolution it won't happen.

MS SCOTT: What do you see in particular needs to be provided by government funding for facilitated community participation if we've already got COAG's agreement to a National Disability Strategy?

DR BAKER (NDS): We have COAG's agreement to a higher level strategy, we don't have any implementation plan as to how that's to happen. I think the National Disability Insurance Scheme should be seen as the platform for that happening. So it's the platform which assists people, people with severe disability in particular who need support services to exercise their rights. The great barriers that people with disability face in Australia are that lack of support. A child with disability can get access, for example, to a mainstream classroom but if that child is just allowed to sit there without support the child will fail. I think that at present the paradigm shift that I think your draft report proposes is a shift to an investment model away from a welfare model of disability support to an investment model and this is entirely consistent with that.

MS SCOTT: In the report on p.21 we refer to community access supports to provide opportunities for people to have, as much as possible, social independence and to provide opportunities for being involved in the community, including leisure, social interaction and so on. I'm still a little lost to work out what more you think needs to be included in the scheme to allow for this community participation but maybe I shouldn't labour the point and just ask you to have a look at what we've got on page 21 and how we've described the work of the DSOs and equivalent of the local area coordination model in WA just to see what else you think needs to occur. I'm open to the suggestion, I'm just finding it a little hard to fathom what it is. John, do you have any more questions for Ken?

MR WALSH: No. Thanks, Ken.

MS SCOTT: Ken, would you be kind enough to answer those questions on mental health interface. We would be very keen to get your organisation's advice on that.

DR BAKER (NDS): Sure.

MS SCOTT: Thank you very much, Ken.

DR BAKER (NDS): Thank you.

MS SCOTT: I now invite to the table Robert Altamore, please. Good afternoon, Robert. Welcome to our public hearing. For the purposes of the transcript, could you state your name please and the organisation you're representing. We have allowed 30 minutes for your presentation and for our discussions and questions.

MR ALTAMORE (PWDACT): Thank you. My name is Robert Altamore and the organisation is People With Disabilities ACT.

MS SCOTT: Thank you. Now, you're opening statement.

MR ALTAMORE (PWDACT): PWDACT is an ACT based organisation run by people with disabilities for people with disabilities. We are an organisation that does systemic advocacy and information; our main area of activity. We work for the inclusion of people with disabilities in all aspects of community activities and removal of barriers for their participation in community. We conduct our work through a human rights framework and within the framework of the United Nations Convention on the Rights of People with Disabilities.

At this stage we are still consulting with our members and with other disability organisations in the ACT about the National Disability Insurance Scheme. So the purpose of our submission today is to highlight some areas of concern that the commission should take into account in preparing their final report.

MS SCOTT: Thank you. Please proceed to the areas you wish to draw our attention to.

MR ALTAMORE (PWDACT): We welcome the report and the commission's work in several ways: firstly, the recognition of the need for additional funding for the services for people with disabilities; we also welcome the commission's approach, which is based on the individual choice and the needs of the individual; and also the commission's emphasis on approach, which is one that people should have an entitlement to a benefit and a service once they're assessed. However, we feel that there are aspects of the model the commission proposes which concerns some of our members. I must say, our members take varying views on the scheme; there's a broad range of views among People With Disabilities on the proposals of the commission.

MS SCOTT: I understand, thank you.

MR ALTAMORE (PWDACT): It's not a uniform approach. I just want to emphasise some of the things that have come to our attention in the course of our discussions and consultations. I'm happy to have a dialogue with you on these things. My first concern is that some of our members are very concerned about the possibility of the scheme being dependent on a new levy or a new tax. They are concerned that the use of an insurance model and an insurance approach, should a question arise of disability and provision of services for people with disabilities in particular, they can see that the thought of a new tax or a new levy may confirm in people's minds the idea that people with disabilities are a burden on the community, rather than encourage the community to recognise their abilities.

Secondly, in terms of the social insurance model, there is concern that if the scheme is like a Medicare-type scheme there may still be two levels of provision. On the one hand, some people will be able to get services quickly and, on the other hand, if it's like a Medicare scheme, there may be waiting periods. An example I might put is, let's say, in a Medicare-type social insurance model those with private coverage can often get their treatments earlier than those who don't have private coverage. For example, in cataract surgery, where if you have private coverage you can get in in three months, whereas if you don't have private coverage you may be waiting a year or two or more. Basically the concern is that the model of the provision that the commission is proposing may not actually eliminate the problems and may cause more problems as more people require services. To build on this, we note the commission's figure for the scheme of 360,000 for the tier 1. We note that there are currently around 760,000 on the DSP. This raises concerns among people and our members as to who is in and who is not in; who the scheme will cover and for what, and who won't be covered.

MS SCOTT: Robert, before you go on further, I wonder if we should pause here, just while I've got a few points in my mind. John, you probably are the same. We'll still give you a chance to continue with your testimony, but I wonder whether we should have a quick discussion about some of these points. Are you comfortable with that?

MR ALTAMORE (PWDACT):   Yes, I am.

MS SCOTT: John, how do you think of that as a modus operandi; do you think that's okay?

MR WALSH: That's good, Patricia.

MS SCOTT: Okay. I've got a few points I would like to discuss with you, Robert, and then maybe John would like to chip in as well. In terms of the concern that a number of your members have that we would be recommending a special tax to fund the scheme: you know how we've got ideas for two schemes, if they're thinking about the large scheme, although a lot of people anticipated that we were going to recommend an increase in the Medicare levy, what we've actually suggested is that what occurs is that it should be net from consolidated revenue, from general government revenue.

MR ALTAMORE (PWDACT): I do acknowledge that is the case, but it was raised in the consultations and in the discussions that had been had.

MS SCOTT: Sure.

MR ALTAMORE (PWDACT): I do know that your first preference is for provision for the scheme from the general revenues of the Commonwealth and that is what we would support, because we believe that people with disabilities should be regarded - and we want to be regarded - as part of the community and not as a special, segregated group for which special levies are imposed to provide for particular needs.

MS SCOTT: All right, so it turns out there appears to be alignment there. On the use of the word "insurance", we do acknowledge as a commission that there is concern about this sense of insuring and being a sense that there might be an inappropriate view that this is about burdens and so on. But really we were talking about an insurance model in the sense of pooling of risk and taking a forward-looking view in terms of the service needs and support needs of individuals. The report does touch on that sensitivity and we're cognisant of it. I don't know if we need to discuss it further here, but I think we have acknowledged that point in the report.

MR ALTAMORE (PWDACT): Yes, I think you have acknowledged it. But what I'm trying to do is convey to you today what we've found in our consultation and discussions so that you can take that into account in your final report.

MS SCOTT: Maybe it's the case that we will take that into account, but it might be also useful, in your feedback to your members, if you indicate that we have actually acknowledged that concern and, in relation to the tax matter, that in the draft report our preference is for general government revenue to be used as funding. In terms of the waiting-period issue and what happens under Medicare, it is very difficult to get across the complexity of this proposal easily. Certainly I've made use of Medicare as a shortcut way to explain to people that there'll be an assessment process and then supports will be provided. It will always be the case that some people will have more financial means than others, but because the scheme is about meeting reasonable and necessary, we're not envisaging that people will be missing out on services because they don't have the means to get services that are reasonable and necessary.

MR ALTAMORE (PWDACT): I guess what we're talking about here though is the area of supply and demand; how the scheme can generate the supply of services to meet with the demand. That is, I think, part of the problem in the medical and other social insurance models. In the end, time and the architecture of the scheme will tell, but again this is one of the things that we are encountering.

MS SCOTT: John, do you want to make any comments at this stage or ask any questions to Robert, or should we let Robert power on?

MR WALSH: I think we should let Robert power on. Just to acknowledge, Robert, that I think that's a good point. The supply and demand issue is one that we are looking at and workforce development will be a critical part of the planning for this model.

MR ALTAMORE (PWDACT): Thank you. I'll continue on.

MS SCOTT: You've still got another 15 minutes, Robert.

MR ALTAMORE (PWDACT): That's fine. I want now, if I can, to talk about assessment. We do have some concerns with the assessment process as the report sets it out. The report seems to present an assessment process, which, although the intent is to be consumer friendly, it's still very much geared on the medical model of disability and the diagnostic model of disability. In this sense, when we talk about the assessment process to people with disabilities, many can feel a step backward. They feel that they're going to be assessed and assessed and assessed and are going to have to demonstrate their disability in terms of the medical and the health aspects. We would like to see the commission, in its final report, emphatically adopt a social model of disability to govern the assessment.

I don't know if the commission has had a chance to fully consider this, but we believe we can find a way to do this and the model we're proposing for assessments is a model taken from the United Nations guidance notes on disability for UN teams in developing countries, and in particular page 14 of those notes, which sets out the assessment process. We ask the commission to seriously look at that assessment process in terms of the way questions are asked in an assessment. As you know, assessments are always a bit problematic and we would say to the commission that if the scheme is going to be effective and do what the commission wants and make adequate provision for people with disabilities and if it's to do what the government wants to do and make Australia fully compliant with the UN conventions on the rights of people with disabilities, the scheme needs to be administered and conducted in accordance with a social model of disability.

MS SCOTT: Thank you for that.

MR ALTAMORE (PWDACT): Can I give you any more assistance there or - - -

MS SCOTT: I've got the guideline in front of me now and I'm just having a little look, but we will look more carefully at this. I think this might have been part of your original submission, was it, Robert?

MR ALTAMORE (PWDACT): It may have been, yes. People With Disabilities ACT put in a submission originally arguing that the scheme embodied the social model of disability.

MS SCOTT: Please proceed.

MR ALTAMORE (PWDACT): The other point I wanted to raise is the treatment of advocacy services by the commission. I should mention that People With Disabilities isn't one of the advocacy organisations in the ACT. In this aspect, we work closely with a number of other organisations, including Advocacy for Inclusion, Women With Disabilities ACT and in particular the Disability Advocacy Network Australia. We've had some discussions among ourselves with advocacy organisations about this issue. From those discussions, we would submit that we would like the commission to go back and reconsider the way it deals with advocacy services. We feel that the commission perhaps has misunderstood what advocacy services are about and what advocates do.

Advocacy services are not like other disability services. They're not the same as provision of equipment, rehabilitation, employment services. They're not a service like that. Advocacy services and Advocates have a special and unique role. They stand beside the person receiving a service as an advocate for that person and what they seek to do is assist the person who is in a less powerful position or a vulnerable position - and many people with disabilities in negotiating the service system are in this position - they assist those people to express their views and to arrive at any outcome in the service provision process which gives effect to those views insofar as that can be done, and which is an outcome which is, as much as possible, the outcome of the person with the disability and not the outcome of either the system or the service provider or the carer.

Thus, advocacy services need to be very strictly independent and their independence needs to be safeguarded. We don't think that advocacy services can be bundled in with a person's other services. There are many instances in which this would be clearly inappropriate. We think it would be inappropriate, say, for example, for a person with a disability that received a service which is substandard, to then have to use some of the entitlements or moneys which they have received with that inadequate service to spend on fixing the problem, if you know what I mean.

Advocacy services may have to, to do their job properly, point to the flaws in the service provision process, they may have to point to inadequacies in the service provision process. They may have to point to, let's say, defects in assessments, defects in the treatment of people and defects in the quality of services. To ask them to do that when they're being funded by the same body that they're criticising is a clear conflict of interest. We're therefore submitting that for advocacy services, there be a discrete and separate and designated - and it should be prescribed and entitled to the pool of funding for basic services, to be separately administered, perhaps by an independent statutory agency or some other independent body.

So what we're saying is that these advocacy services are to come under the scheme, the scheme would recognise that they are not advocacy services, they are a service which stands alongside the person and that their funding and administration be conducted in a way which safeguards the integrity of advocacy and the integrity and independence of advocates.

MS SCOTT: Thank you. Any further points, Robert?

MR ALTAMORE (PWDACT): I think I have covered the gist of most of the points in my printed submission, which I don't have in front of me.

MS SCOTT: I've got it here in front of me and I think you have - - -

MR ALTAMORE (PWDACT): But I'm happy to take any questions or enlarge on any of the things that you would like me to enlarge on.

MS SCOTT: Thank you. John, do you have any questions or comments for Robert?

MR WALSH: Robert, that was very helpful. Thank you very much.

MS SCOTT: I found it particular, Robert, so thank you. I don't have any further questions for you.

MR ALTAMORE (PWDACT): Thank you.

MS SCOTT: We'll take a five-minute break.

MS SCOTT: Good afternoon and welcome to the table, Graham and Peter. Would you like introduce yourselves, because we have a transcript and a recording being taken this afternoon. Then make an opening statement and John and I may have one or two questions for you. We've allocated 20 minutes for your presentation and our discussion. Over to you now.

MR WAITE (TADACT): Firstly, I'll introduce myself: I am Graham Waite; I'm the executive director of Technical Aid for the Disabled ACT, based here in the ACT. This is Peter.

DR McCULLAGH (TADACT): A member of the board at TADACT.

MS SCOTT: Thank you.

MR WAITE (TADACT): We have forwarded some key points that we wish to raise with you. Perhaps I should talk to the first one. We felt that it was important to raise the issue of education and give it more profile in this whole investigation on the basis that the early education is going to help with the people being included better through their later life and prepare them for various life issues that will come along. So an example that we've got - Peter will just pass to you there.

MS SCOTT: Thank you very much.

MR WAITE (TADACT): That shows a graph of the last 250 or so projects that we've done with TADACT and the age profile. What we're seeing is that there's a lot of projects that come along that we see benefiting the younger children, especially the nought to 10s and perhaps, say, the 10s and the 15s. We're seeing that the early giving them equipment, giving them solutions, is going to help them and is certainly setting them up for a more successful process of dealing with challenges in later life. We've got an example, a little newsletter we've got here. I'll just talk to that. This young boy, he's now 10, but he's had this special stander that allows him to participate in a regular school. So he's at a primary school, he's able to do things in a similar manner to other children. He wouldn't normally be able to stand up, but with the aid of the stander he can not only participate in the school activities, but whilst he's doing that he moves around a bit and that helps him develop his hips. His bone structure, his spine structure will improve whilst he is doing that.

We've done this for a number of children in recent times and we're finding that we're getting a lot of inquiries from occupational therapists and other health professionals for other specialised equipment for younger children, often to be used at school, but also sometimes we get requests for a similar set of equipment for the child to use at home as well. The equipment may be used for learning, for play, for eating, education, whatever; it's a mixture. But we certainly would emphasise that point. Would you like to add on education?

DR McCULLAGH (TADACT): The second-last word that Graham's mentioned, "emphasise", I'm sure that you have a very large report and probably mention numerous things that we feel - this early intervention, enabling education, gives an opportunity for a child when they grow up, and most of these children are going to have a disability going for the next 60 years. If you're looking at quality-adjusted life values - this is one of the things that the economists tend to talk about - you've got a terrific investment here in 50 or 60 years. From a humane point of view that's highly desirable, because people get the opportunity to realise their potential as much as possible. But from an economic point of view - and I realise that everything has to be passed through economists - if you can intervene at an early stage and equip a child to be able to get opportunities, educational, recreational, and socialising, et cetera, that they would not otherwise have, the likelihood is that the subsequent costs to the community are going to be considerably less.

Very much for TADACT, the other point about a young child is that they don't come in one size or stay in one size, unless they've got some disturbance of growth, their epiphyses are fused early, they're going to require updating and Graham can tell you how this is done. Maybe it's just modifying or producing new equipment, but you'll see from that graph. We can't claim that we know everyone or have a representative sample of people with disabilities in the ACT, but the sample we get, that is overwhelmingly a very important group. Graham?

MR WAITE (TADACT): Yes. It actually is an interesting point you raise. We only get to see a small proportion of the population. We're doing about 300 projects a year and, from the statistics from ABS, there's a lot more that we don't see. I guess that's a challenge for all concerned in the industry. In some cultures, if there was a disability, the child is kept away from the rest of the population. I fear, to some degree, that still happens here. It's far better than it used to be and I have spoken with people; for example, someone who has had a child with disabilities who was growing up in the 1970s and she said in that era, in Australia and here in Canberra, very much it was the case you kept the child away from everyone else because you'd done something wrong and you'd had a child with disabilities. That's very sad; hopefully we'll move on from that.

The second point we'd like to raise with you is the assessment process, which we understand that it is a very important process, but we would encourage that there'll be a question in that assessment process that deals with the issue of equipment that is going to improve the quality of life and the inclusion for the person involved, whatever age this assessment might occur. Now, I know the assessment will be dealing primarily with their living arrangements and their family arrangements and the various supports described in your report but we would certainly strongly recommend that there is a question there that says, "Look, early provision of some specialised equipment may help this person develop in a way that they might not have otherwise done."

I guess there is a corollary to that. Some of the equipment that is available is of horrendous cost and if they have to make judgments about how they're going to be using the money that's available to them, I would suspect that, as I think there were some other comments in the overview there, that quite a few of the people are going to need some assistance in making decisions because there are some pretty expensive bits of equipment around. The worst I have heard of recent times is a powered wheelchair and $32,000 I think it was. That's scary when you've got to trade that off against other things that may be benefiting the person that could be bought if that was an allocation of money.

The third point was really, I guess, to reinforce the fact that there are groups of volunteers around the country who are able to provide affordable customised solutions. There is a Technical Aid to the Disabled group, whatever it's actually formally termed, in every state but not in the Northern Territory. They, like we do in the ACT, deal with challenges on a day-to-day basis and try and find solutions with the actual labour content of the work being done by volunteers, so that's how the affordable solution comes about.

DR McCULLAGH (TADACT): Reverting back to the second point, just the problem of ascertainment. As one senior representative sample and being able to know exactly what disability is out in the community. We obviously don't see a representative sample, we get a chance referral by an occupational therapist who knows about us, but there are many occupational therapists who may not know about us. So what we really think is the more that this can be brought to the awareness - the assessment process that you are proposing is great and that obviously is going to be the best ascertainment there has ever been, that you are going to see what disabilities are there, that at that early stage it's virtually a mandatory question, "In you opinion" - and this is the assessor's opinion - "do you think that this individual could now or later benefit from specific aids" - as Graham mentions - "and is it appropriate if you think it might be later that there be a review of the person, a new assessment scheduled one, two or three years down the track." If you see a child before it would normally be walking very much, perhaps you would want to reassess aged four or five and see, "Well, has it managed to progress?"

The third point that Graham mentioned, TADACT has perhaps 30 or 40 volunteers who may not be working all the time, it depend on what project is required. Clearly what we're foreshadowing is that if you get decent ascertainment, decent referral the actual unmet need is going to be seen to be much greater than it is at present and there is a lot of scope for volunteerism. We're not here to press TADACT. We're flat out as it is coping with what we can and surviving. But there is going to be a big unmet need for volunteers. With early retirement I think a lot of people in the community have skills like that and if this could be put in a formal sense into the assessment process, "Have you considered this?" and, "Is there anything you can see which now or in the future might be relevant?"

MS SCOTT: Very good. Thank you very much.

DR McCULLAGH (TADACT): So those are the three points.

MS SCOTT: John, some comments.

MR WALSH: I was a client of TAD in New South Wales a few years ago so I'm well aware of the work you guys do. I think it's a great organisation and the thing about it is the quality of the people who provide these services are usually very skilled workers who have retired. I would be interested in just an overview of how many volunteers there are around Australia that are members of TAD and any information you have on how many projects are actually undertaken in a year.

MR WAITE (TADACT): I can give you the ACT one. We currently do somewhere between 300 and 320 projects per year as defined by the ACT government. That includes giving some referrals and some advice. So some things don't result in a hardware solution. We have currently around about 50 volunteers and that is reasonably representative. I'll take on notice, if I can, and provide to you the statistics for the other TADs. I am actually wearing another hat as well and that is I'm here as the secretary of TAD Australia and I will consult with the other TADs to give you the other figures, if that's acceptable to you.

MS SCOTT: That would be most welcome. You didn't hear one of our earlier speakers but we have been encouraged to consider how the scheme could make better links to the community groups that already exist. I suppose this is a very good reinforcement of that message actually having you along this afternoon. The timing couldn't have been better if we had organised it.

You highlighted the fact that occupational therapists know about your work. We have suggested that at tier 2 of the scheme there almost be a referral service, that people who are looking for information may not need an individualised funding package but may need assistance in another area would be able to go onto a web site and quickly find services available or approach the organisation, the NDIA, and seek assistance and then have an effective referral, not just, "Here's a phone number. Good luck, see how you go." Are you aware of any good registry service or any web site that effectively brings together all the volunteer groups operating in the disability space? We're not aware of anything but I just wanted to check.

MR WALSH: No. We have our web sites, there is a TAD Australia one and there is a TADACT one and there is one for each of the other TADs. It is an interesting question. On the equipment side, the Independent Living Centre has a very comprehensive database which allows people to find, with assistance, solutions to their problems or, if there is a need for a customised solution, that's how our organisation might be involved. Certainly on the equipment side there is something there that might help but not in terms of another overarching web.

DR McCULLAGH (TADACT): Just taking up that point. It's true to say that frequently people not having access to community services, even though they're there, just means that they don't know about them. A web site sounds a great idea but there would be a substantial number of people who might not have that sort of access or technology and think a mouse is something that runs around on the floor. I think one could be inadvertently discriminating and selecting out the educated group. I'm sure you've talked to many people but I've known quite a number, from a family point of view people with very disabled kids and virtually their whole life revolves around that, their occupation, their holidays they disappear. I think it would be good starting off at least for some years to have something that was more proactive.

For example, working through ethnic communities, for example in Cabramatta, I suspect - and I may be wrong - but that the Vietnamese community there may not be attuned to going into a web site and looking for disability. Again, this comes back to keeping the thing in reasonable cost terms, there is scope for volunteering in a lot of areas and one of the areas for volunteering could be people going out trying to dig these things out and promulgate the idea. Any decent community social service in the future has to rely heavily on volunteers. The money isn't going to be there, we realise that. TADACT is an example of actually one group of volunteers producing things, but you can have other volunteers who are helping in other ways and trying to bring people in who might otherwise miss out.

MS SCOTT: That's a very good point. Thank you, Peter. That's good.

MR WAITE (TADACT): The point about the migrants is interesting. I was looking at some data recently. Apparently the ABS figures indicate that people from non-English-speaking countries, the rate of disability is much higher. I don't know whether that has been drawn to your attention.

MS SCOTT: It has, about two days ago.

MR WAITE (TADACT): So 45 per cent, which I find - wow.

MS SCOTT: Thank you very much for coming to the hearing and drawing our attention to these three issues. We should commend you on your work. So thank you for making the time today and also for your work in the community. You've highlighted an important aspect to us this afternoon. John, anything further you wish to add?

MR WALSH: No. Thanks very much, guys.

MS WAITE (TADACT): We should put in a submission basically just fairly concisely outlining the points we've made.

MS SCOTT: Just the points you've made today would be fine. Thank you.

DR McCULLAGH (TADACT): We'll add in those statistics that you've asked about.

MS SCOTT: Yes, please. Thank you very much. Thank you for also this material.

MS WAITE (TADACT): Thank you.

DR McCULLAGH (TADACT): Thank you.

MS SCOTT: John, Robert Altamore has just requested that he has an opportunity to make a few additional points. This won't take long, but I'll invite Robert to come forward now.

MR ALTAMORE: Thank you. I shall be brief. I wanted to do this separately because it is personal, rather than part of my submission for the organisation for which I work, but I actually am a blind person and my preferred method of communication is braille and I did have extreme difficulty in dealing with this report of 810 pages because I could only get about a tenth of it, that is the summary - it might be less than a tenth, about 60 pages of it - in my preferred mode of braille due to what the commission staff claimed were cost considerations. They claimed it would cost $20,000 to do the whole report. I don't know if that's right or not, but that is what they were told.

The bottom line is that I could not access the report as I would have liked to have accessed it and in that sense, I've had difficulty in sort of dealing with it. I just want to mention there is a right of people to have access to information in their preferred format, particularly in braille. That is recognised by the United Nations convention and I think the disability service needs to recognise that.

MS SCOTT: Thank you, Robert. I might just take the time just to clarify to see if I understand your situation a little bit better. I know that we have put material out in RTF, Word and DAISY formats and I think we've had success in also putting things out in the format that will allow people who prefer to have a very simple English picture format available. As you said, I think the overviews have been available in braille, but we do want to hear if there's any problems, so thank you for drawing those to our attention.

In terms of the cost, I think the team has gone ahead and sought costs of producing the report in braille and I'm advised that it would be a considerable cost, 3000 braille pages. At this stage I think the commission has asked you to consider what your requirements are, given the other formats that are available and I think you're in the process of considering your position. Have I got that correct?

MR ALTAMORE: That's fine, but I wish to take it beyond the personal here, if I can. In the end, this final report will be one of the seminal documents for people with disabilities in Australia. This reform is being promoted as one of the most major things to happen to people with disabilities since the Disability Discrimination Act. I would hope that for the sake of others who may want to read this in their preferred format later on, even once the final report is done, that there will be a number of copies braille.

MS SCOTT: All right, Robert. Thank you for that response. Is it possible that electronic braille would be acceptable to you, do you think?

MR ALTAMORE: I've used electronic braille and I've had use of it. I have been able to use electronic braille to read elements of the report, but an electronic braille system costs up to $10,000 and most people with disabilities can't afford that. In many cases, the only people who have them are people who have got them through workplace modifications.

MS SCOTT: So, for your own circumstances, if the final report was available in electronic braille format, that would be acceptable to you, for your circumstances?

MR ALTAMORE: I could read it, put it that way, but as a systemic advocate, I believe that people who don't have access to synthetic braille - I should mention, when you say it's available in synthetic braille display, that means you use your speech on your computer to read and it comes up in the braille display, so basically the braille display is something attached to the computer, it's not the document being available in a different format.

MS SCOTT: I'm sure you're more precise in your terminology than I am.

MR ALTAMORE: I think that for those people who don't have access to synthetic braille, there needs to be provision. For example, many people are deaf and blind and they only have braille, they don't have the option of speech.

MS SCOTT: Yes, all right. Thank you for coming forward and making those individual comments. John, are there any questions you have for Robert?

MR WALSH: Thanks for bringing that to our attention, Robert.

MS SCOTT: Thank you. I think, unless you've got anything further to add, Robert, I might now adjourn the hearing for today. Nothing further to add, Robert?

MR ALTAMORE: No. Thank you very much.

MS SCOTT: Thank you for your time. So I take pleasure in adjourning our hearing and we'll resume in Brisbane. Thank you.

AT 4.28 PM THE INQUIRY WAS ADJOURNED
UNTIL MONDAY, 11 APRIL 2011