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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT SYDNEY ON TUESDAY, 20 JULY 2010, AT 9.31 AM

Continued from 19/7/10

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MS SCOTT: Good morning. Welcome to the public hearings of the Australian Productivity Commission's inquiry into disability care and support. Thank you for attending today. My name is Patricia Scott. I'm the presiding commissioner of this inquiry. My fellow commissioners are David Kalisch, who will be joining us later, and John Walsh.

The inquiry started in April with a reference from the treasurer. The Australian government has asked the Productivity Commission to examine the feasibility, costs and benefits of a national disability scheme that would provide long-term essential care and support; manage the cost of long-term care; replace the existing funding for those people covered by the scheme; take account of the desired and potential outcomes of each person over a lifetime with a focus on early intervention; provide a range of coordinated support options including accommodation, aids and appliances, respite, transport, day program and community participation; assist people with disabilities to make decisions about their support; provide the people to participate in education, training and employment where possible. The Australian government has asked the commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options including a no-fault social insurance model and approaches used in other countries.

We have already talked to a range of organisations and individuals. We will be moving next on to Perth and then we will finish our first round of hearings. We released a discussion paper, issues paper, at the end of May. We are grateful for the submissions already received and submissions can be downloaded by going to our web site at www.pc.gov.au. We would like to get submissions as early as possible but we have extended the due date for initial submissions to Monday 16 August 2010. The commission welcomes second and even further submissions. These submissions may include additional points you wish to make, comments on other people's submissions or other organisations' submissions, and results of community consultations. Please feel free to make those extra submissions if you wish. The purpose of these hearings is to provide an opportunity for interested parties to discuss their submissions and their views on the public record.

We would like to conduct all hearings in a reasonably informal manner but I do remind participants that a full transcript is being taken. For this reason comments from the floor cannot be taken but at the end of today's proceedings I will provide an opportunity for anyone who wishes to make a comment to come forward. Participants are not required to take an oath but are required under the Productivity Commission Act to be truthful in their remarks. Participants are welcome to comment on the issues raised in other submissions or in other presentations here today. Transcript will be made available on the commission's web site following the hearings. This is a good time to think about your mobile phone; is it off or on silent?

We'd welcome you switching it to off or silent because we are making a transcript.

Are there any media representatives here today? No? Thank you. To comply with the requirements of the Commonwealth occupational health and safety legislation you are advised that in the unlikely event of an emergency requiring the evacuation of this building, please follow the instructions of the hotel staff. If you require assistance please see Hudan or myself and we will be happy to assist you. I would now like to welcome ACOSS to the table to make their presentation.

MS BOYD-CAINE (ACOSS): Thank you.

MS SCOTT: Good morning.

MS BOYD-CAINE (ACOSS): Good morning.

MS SCOTT: For the record please, could you state your name and your organisation? We have about half an hour. We'd like to have an opportunity to ask some questions so if you could take that into account in terms of the timing you'd like to make for your first statement. Thank you.

MS BOYD-CAINE (ACOSS): Thank you. My name is Tessa Boyd-Caine. I'm senior policy officer at the Australian Council of Social Service. The Australian Council of Social Service will be making a written submission to the Productivity Commission. That submission will be coordinated by ACOSS but it's on behalf of the COSS network, so that's the Council of Social Service in each of the states and territories as well as ACOSS. What we were hoping to use our time today to do is really to raise some questions and to, I suppose, put those on record as questions that we regard as key to the inquiry but also to get some indication or some steer from the commission if you're already minded about some of the issues that we're considering, which would certainly be useful for us in terms of tailoring our submission.

To start with, we take a number of premises as read and are not planning to address them in our submission. I suppose the first thing to say is that we start from a position of entitlement, particularly in relation to social security but also in relation to broader benefits than social security. We take human rights as a guiding principle that matters very directly to a lot of the issues that we're talking about in the scheme and in our own submission but we don't intend to address those in much detail. We know that you've received submissions on those already and there are organisations involved in this process that are better placed to give you more detail about that; but we want to make it clear that we see those as integral to the process.

The other premise that we start from is that there are organisations that have been involved in advocacy to begin this reference and certainly have been giving evidence to you about the experience of living with and caring for disabilities. We are very supportive of the government's funding to a number of those peak and representative organisations. So once again, we regard them as better placed to give you evidence about that and won't be addressing those issues despite the fact that our role as a peak body involves working very closely with a lot of those organisations.

Where we think ACOSS can add some value and provide some useful input for you in relation to this inquiry is in the question of the design of the scheme. So our questions and discussion today is very much about those design features, and that's something that we will be focusing on in our written submission to the Productivity Commission. I suppose I say all of that because if there are other areas in relation to the scheme or the inquiry that you are interested to hear from us about, we would certainly welcome your instruction in that regard. I have provided a guide to our oral submission today. Have you received that?

MS SCOTT: Yes, we have.

MS BOYD-CAINE (ACOSS):   It was submitted very late in the piece. I apologise for that. So we raise a number of questions in relation to the design of the scheme. As I say, we're certainly keen to hear from the Productivity Commission if you are minded in certain directions about that. Of course we have some suggestions and we have some proposals around some of those questions but they are very much fresh in terms of capacity to work on them.

I suppose the two key issues that we regard as essential at this point in the inquiry are firstly in relation to how the scheme sits with other existing schemes. We would include within that the question about social security but we would also see policies around aged care and around health care as existing policies that the scheme will need to negotiate in some form or another if it is to - both to be effective but also to meet the currently unmet needs and not to cause confusion, I think, with some of the existing policies in place around those issues.

So we see that as the first key question in relation to the design of the scheme. The second key question is really about how to determine entitlement in terms of access to the scheme. I suppose put more directly, we are interested in what might be the areas of exclusion through which eligibility for the scheme would be determined. We realise that that's controversial and that's difficult but we also think that it's absolutely vital that the scheme's effectiveness and its adequacy in terms of, as I say, much of the unmet need, is determined on the basis of clear areas around entitlement.

MS SCOTT: I wonder if you can keep your train of thought, Tessa, and I could just clarify something. Are you suggesting to us that we should be thinking about these or are you suggesting that you're going to be presenting material on those two topics in your submission. I just want to clarify, because we've gone out with the issues paper and said one of the key issues is eligibility. Have you given it some thought already and do you have a view on what that should be?

MS BOYD-CAINE (ACOSS):   Yes to both of those questions. So we have given it some initial thought and I suppose we were hoping to hear from you about whether you've moved any further down the track in terms of some of the areas that you'd be looking at or excluding around entitlement before we move further.

MS SCOTT: All right. Look, one of the things, that as I read out at the start, the purpose of the public hearings is to actually hear from the public and from organisations and from individuals about their ideas. We want to then hear from everyone, consider it and think about it and then put out a draft report in February. So I guess we're not going to be indicating today what our views are about eligibility - not because we don't want to be open with people but we're still getting submissions from people, we're still in the listening phase. So it might be more fruitful if you share your ideas with us. I mean, we're still receiving submissions and, as I indicated right at the start, the due date for the first set of submissions is 16 August. So maybe this is not, I guess, the right time, I'm suggesting to you, that you'd be putting questions to us. We'd be keen to hear your views and then we can take those on board. Okay?

MS BOYD-CAINE (ACOSS):   Sure. I suppose taking the first question about how does this scheme sit with existing policy frameworks, one of the areas that has, I think, been quite contentious for us in our discussions with our members has been the question about ageing and aged care. We realise that you were given a specific reference in relation to that but I suppose the concern that has come from discussion with both members who represent people with disabilities and their carers but also service providers is how you forge that distinction in practice, which I'm sure is not the first time you've heard that issue.

It strikes us that there are some quite straightforward ways of forging that distinction and that's around institutional care. So we would see that aged care within an institutional setting is clearly identifiable and able to be separated out from issues around the scheme in much the same way that care within a hospital setting is clearly identifiable and able to be separated out from the context of this scheme. But the issues around disability brought on through the process of ageing and some of the health needs of people with disabilities is something that has vexed our members, particularly around service provision. I suppose that's particularly for services that provide services in a number of those areas.

MS SCOTT: Would you be comfortable if we ask questions as we go through this?

MS BOYD-CAINE (ACOSS): Yes.

MS SCOTT: Just on that, we've heard, and there's plenty of evidence to say, that there is quite a number of young people who are in aged care facilities where they are much, much younger than the rest of the population in those institutions and they're there because they've got high support needs, there is inadequate accommodation and they're young people with disabilities. So I guess I'd be worried about a definition which is defined by institutions because we already know that some of those people would prefer to be in other settings. Would you like to comment on that? I'm not showing a lack of interest - my pen doesn't work. I'm just going to dash to the back of the room while you think about that and maybe give an answer.

MS BOYD-CAINE (ACOSS): Sure. I mean, I think there's questions about policy and there's questions about the best interests of people with disability and the policies don't always ensure that the support needs for people with disabilities are met. I mean, I think that's well accepted. So I suppose we would see that the support needs of a person with a disability is the priority and the question is how best you meet that. I think that evidence goes to show that the needs of those people are not best met. So it's not that we're suggesting that institutions form the basis for inclusion or exclusion of the scheme, but ideally, aged care institutions are for people requiring care in relation to their ageing and you could argue that young people with disability who are in those institutions are not there because that's the best way to meet their needs.

I think quite often they're there because it's the only way that the authorities or their families or carers have seen that their needs can be met. So I don't see that that confuses the issue. In a sense, to me, that's an example of those needs not being best met and we would hope that the scheme and whatever supports are in place as a result of that would be able to address that problem.

MR WALSH: Can I take it from the other direction, please, Tessa. So let's think about people who are ageing who have high support needs and are supported in the community. Are you suggesting that those people may be covered by this scheme that we're talking about?

MS BOYD-CAINE (ACOSS): The question about community care is the one that we regard as absolutely central, so I don't think that we would be arguing - ACOSS isn't looking for one structure that captures all of those needs. I suppose what we're interested in is thinking through how this scheme might sit with those existing policies and in a sense wanting to protect this scheme from being seen as a default response to unmet need in other areas. I suppose that's really where we're coming from. So central to our submissions around the design of the scheme would be that it sits next to social security but clouds some of the provisions within social security. Carer benefits would be an example where we would regard those as an important part of the social security system and needing to remain within the social security system but that's not to say that there won't be support needs for carers that we would see as rightfully placed within the scheme.

So I suppose what I'm trying to say is that we see an important question around the design of this scheme, being how do you deal with the fact that there are other policies and structures in place that will intersect with some of the issues that the scheme is intersecting with and that they need to not be competing but there need to be quite clear guidelines and parameters around those.

MR WALSH: Yes, okay. I understand. So do you have a view on who should be eligible and what should be covered by the scheme?

MS BOYD-CAINE (ACOSS):   Yes, we have views around some of the issues that we've raised in the oral hearing submission and some of them we will be coming back to you with much greater detail in the written submission. One of the things that we've been looking at is the idea of the entitlement as a benefit entitlement in a sense. So we suggested in our oral submission that there's three ways that you could be looking at the entitlement: one could be a cash amount, one could be a guaranteed package and one could be a cash allowance tied to a set of services. Now, there's much debate around each of those and we acknowledge that this is a fairly controversial issue but we do think that there's a case for the third option being the benefit option because we see that it provides a framework for ensuring an efficient of that entitlement, which is a really key aspect in terms of questions about unmet need but also improving the support that is already available.

We also think that that's a good way of separating this scheme from some of the other cash supports that are available, particularly around income support, but I think the question around efficiency and effectiveness of those supports is very much around how the service is defined. I suppose that's where we come to absolutely supporting the idea that the guiding priority and principle must be the support needs of the person with the disability and, related to that, their carer. So we accept that that needs to be the principle, and the key principle, for the scheme but the question about the sector that provides that support is obviously integral, and so how you ensure that the industry or the sector, in whatever form it takes, is adequate, is capable, is able to meet those support needs effectively is obviously a key question.

As to, I suppose, how you might look at services - you know, questions about funding and questions about sustainability of that sector - we see that as being secondary to designing a scheme that best meets the support needs of people with disability.

MR WALSH: Do you have a view how those systems might be developed?

MS BOYD-CAINE (ACOSS): The systems for?

MR WALSH: Support needs.

MS BOYD-CAINE (ACOSS): Support needs. We are certainly intending on addressing that in our written submission. I think it's fair to say that it has been a pretty strong debate within our membership and there are still some discussions that we're having with our service members as well as with our members who represent people with disabilities. I mean, we think there are some examples that are currently being trialled that are certainly showing benefits around individualised approaches to support needs. One of the problems that we've had is that the design of those services is often linked to funding and in a sense we would be saying that the funding questions need to flow from the design. So getting clarity around what that might look like has been a challenge for us in terms of discussions with our members but I would say that in terms of the written submission we'll be able to address those questions.

MR WALSH: I guess just getting into that in a little bit more detail, if ACOSS has a view on the relative merits of block funding to service providers versus individualised funding to people with a disability, that's a fairly key question that's coming up.

MS SCOTT: Tessa, while you're writing down the homework list I guess the eligibility issue relating to people with mental illness is quite a complex issue. The issues paper referred to the fact that a lot of people have temporary experiences with mental illness and with treatment those problems go away and other people have a lifelong issue with mental illness, possibly episodic. How they should interact with the scheme and what the scheme should have available for them is an issue that we have invited public comment on.

MS BOYD-CAINE (ACOSS): I will say in relation to that one of the things that we've been concerned about in relation to the health reform process has been the focus - again the focus on institutions in terms of hospital care we think at the expense of proper development of primary health care and community support settings.

So to the extent that - having said that we - you know, that we certainly support it and see it as important to keep the health system and the disability support system separate, we do think that there are ongoing issues in relation to some of those questions, particularly around capacity for support for people with mental illness that remain unresolved even in the current health reform agenda. So that's certainly advocacy and policy work that we are continuing on. It's something that we hear from services time and time again, that services - you know, ranging from disability support services to emergency relief services - are constantly needing to be able to, and be equipped to, deal with issues of both diagnosed and undiagnosed mental illness within their client groups.

We would hope that the capacity for adequate community support for mental illness would be addressed within the health reform process, but as I say, we've been concerned at its absence so far. It might be that adequate community support and primary health care was a way of addressing at least some of those issues, obviously not all of them, but we are certainly pursuing that within the health policy process.

MR WALSH: Would you regard that the - I mean mental illness is a health condition requiring health intervention but some of the outcomes of mental illness are functional activity limitations which are disabilities. Would you regard some of the activity limitations that result from mental illness being covered by this scheme that we're talking about?

MS BOYD-CAINE (ACOSS): I mean we would imagine that some of them would be - in the way that there will be health needs associated with disability that are not well addressed within the health system and are significant factors for people with disability and they will need some support within this scheme. In our submission we talk about areas where co-payments are required or areas where the PBS has been specifically narrowed but that has a disproportionate impact on people with disabilities. In very much the same way we would see that there's elements of mental illness that will have a disproportionate impact on people with disabilities. So we would hope that - and certainly look to a design for a scheme that was able to address that insofar as it affected individuals without necessarily seeing it as a mental illness support scheme by proxy.

MR WALSH: Certainly psychiatric disability is within our terms of reference. So if you could address in your submission the extent to which the health and disability systems work with each other with respect to mental and psychiatric disability, that would be good.

MS BOYD-CAINE (ACOSS): Okay. Can I ask whether you've received evidence in relation to the risk principles of an insurance scheme? Something that we've been looking at and wondering how much to address is that question about the insurance scheme based on a sort of traditional approach for an insurance scheme based on principles of risk as opposed to a broader approach to support needs.

MR WALSH: Can you explain what you mean by principles of risk?

MS BOYD-CAINE (ACOSS): I'm thinking back to a forum that I heard you speak at Darling Harbour at a Labor Party fringe forum last year which was, I think, organised by the young people in institutional care alliance. There was discussion there about some of the accident insurance schemes in other states, I think in particular the Victorian state, where the insurance scheme - the TAC scheme, I think it is there, runs very much along those lines but is very much geared to, as I say, accident or acquired injury. I suppose there are ways of defining risk in relation to those issues that don't necessarily apply across the board. So that's - I suppose that's something that we were taking into account in thinking about to what extent this is seen as an insurance scheme. But it strikes us that a lot of discussion and a lot of the submissions so far have been about a much broader support scheme.

MS SCOTT: When I read out the introduction, Tessa, I made reference to social insurance. I guess that's - the joining of those two words is very important. So Medicare is a social insurance scheme. It's a pooling of the risk, because we all pay taxes into that scheme and effectively some people are heavy users of Medicare and other people are light users of Medicare. So I guess you might want to take into account in your deliberations the social insurance concept rather than I guess, a commercial insurance concept. That might help you a little bit.

MR WALSH: Yes, I think the TAC scheme and the lifetime care scheme in New South Wales have emerged out of a private insurance model of compulsory third party insurance. So the premiums paid by motorists are determined by the nature of their vehicles, which is sort of a semi-risk graded scheme. That's one option for collecting premiums in some areas. In this area of disability, as Patricia says, it's a bit harder to attribute risk or cause. So I guess we'd be interested on your views on the best way to collect premiums but social insurance is really a more broad-based collection process.

MS BOYD-CAINE (ACOSS): In our submission to you in relation to the oral hearings one of the things that we wonder about is that relationship between, for instance, workers compensation schemes and the design of this scheme. We would see it as important that the entitlements and eligibility remain separate but we were wondering whether there was capacity for the new scheme to cooperate in some sense with some of those existing schemes, for instance, as a way of pooling some of the resources. Now, if you are interested in that idea and if you are looking at how that might work, obviously maintaining the integrity of each scheme is really important but that question about how you resource the scheme is one that we've certainly been considering.

MR WALSH: That would be useful to get some information.

MS BOYD-CAINE (ACOSS): Okay. I'm mindful of time. I don't - where are we up to?

MS SCOTT: We've got about two or three minutes left.

MS BOYD-CAINE (ACOSS): Okay.

MS SCOTT: So you might want to sum up.

MS BOYD-CAINE (ACOSS): Sure. I mentioned that we see the priority consideration being around the support needs of people with disability but the question about what services underpin that is obviously key. Something that has been discussed at the outset, and I think probably prior to the establishment of this inquiry was very much the issues around individualised funding agreements and individualised service models and the question about whether there was a tension between those and services in terms of issues around service sustainability. I think it's fair to say that in our discussion - and it's probably important to say that in our discussion with our members that issue has not been raised as something that vexes services. So in terms of how you prioritise those issues it's just really to affirm that we see the best support system as the priority but we would also regard it as very important to factor in how services best meet those needs and service sustainability is an issue in that context, not in terms of service sustainability itself but in terms of ensuring those support needs are best met in an ongoing way where they need to be. So the question about workforce is really important there as well as the question about capacity and effectiveness of those services and those are all issues that we'll be looking at in slightly more detail in our written submission.

MS SCOTT: Thank you very much for coming along and thank you for taking down a list of homework. I guess we'd look forward to seeing how ACOSS takes the principles that it's outlined to us and proposes that they be reflected in a design of a scheme and operationalised in a scheme. Thank you coming along today, Tess, and we look forward to getting your formal submissions.

MS BOYD-CAINE (ACOSS): Thank you.

MS SCOTT: I now invite to the table Michael Bleasdale. Michael, thank you for coming along. For the record could you identify your organisation and state your full name please and would you like to make an opening statement.

MR BLEASDALE (PWD): Thank you. Yes, my name is Michael Peter Bleasdale. I'm here as one of the three executive directors of People With Disability Australia Inc. In terms of an opening statement, I don't think there's anything groundbreaking that I can probably say, the scope of this inquiry is so enormous and I think we're taking the task very, very seriously. People With Disability Australia is a cross-disability organisation, disability rights and advocacy is its focus. It has a national and an international scope and I suppose one of the key things to say at the outset is to say that we welcome the inquiry. We are committed to providing to a very comprehensive submission. We're also committed to consulting as widely as we can with members, so that's people with disability and cooperating with colleagues in the disability sector to try and get as much information and expertise into our collective submissions that's going to assist the Productivity Commission.

We feel that we agree with the overall premise that the current service system as it's in operation across Australia is not working. It doesn't really meet the needs of people with disability according to their expectations and that this is a tremendous opportunity to actually develop a new disability system that will actually meet those needs but in doing so we have an enormous task ahead of us to get the detail right and to get it right at a whole range of levels. I guess the only other thing I'd say at the outset is that work has begun within the sector and PWD and AFDO and a number of other organisations have been driving this to ensure that any new system that comes into play has to really stick very closely to the expectations that we have now with Australia being a signatory to the United Nations Convention on the Rights of Persons with Disabilities. So again in our final submission there will be a lot of referencing of that and how to put that into practical application.

MS SCOTT: Are you comfortable if we ask you questions at this stage.

MR BLEASDALE (PWD): Yes, absolutely.

MS SCOTT: Michael, given your organisation puts considerable emphasis on advocacy and disability rights, what are some of the safeguards that you'd like to see built into a scheme and can you refer to good arrangements that exist either here or overseas that we should look to in terms of design of those elements.

MR BLEASDALE (PWD): Safeguards from the point of view of people with disability getting the kind of services and supports that they require?

MS SCOTT: Yes.

MR BLEASDALE (PWD): I'm going to answer this is a fairly general way. We would very strongly advocate for what is already on the table which is that any new service system be administered on the basis of individualised supports. There are a number of us - and I've got another hat on with In Control Australia - a number of us who are very strongly promoting that that be in the form of truly individualised funding that's paid directly to the individual. We think that by paying funds directly to the individual and the individual being in the position to make decisions and choices about the nature and type of the services and supports they receive will fundamentally change the way that supports are delivered because they have to become much more accountable.

So that, I suppose, answers the questions about how we can improve the system by actually making it much more a system that funds the demand side rather than the supply side and, as I said, making those agencies and those individuals who are charged with the responsibility of delivering support much more accountable to the individual. There are, I think, quite a lot of overseas experiences and evidence that this kind of thing works. It's not necessarily a system which will be able to be operated any cheaper than the system we've got and that's the other thing to stress and I think we've already accepted that the current disability system is not adequately funded. But certainly there is enough evidence from overseas, and again this is the sort of evidence that will be put into our final submission, that even though there's not necessarily cost savings when we individualise a service arrangement, there are significant benefits in terms of the outcomes and the quality of the support that's provided.

There aren't too many examples in Australia and I actually don't feel as if I'm the authority to talk about those examples here in Australia. But one example that I think does demonstrate that point quite eloquently is the scheme in New South Wales to provide funds for attendant care directly to people with disability and just the difference in the control they have over they support they have with exactly the same amount of resources, I think, demonstrates that point quite elegantly.

MS SCOTT: We have heard a lot about individualised support and we have done quite a bit of work already on that idea, so we'll take your comments on board but thank you for that. I was thinking of things after an assessment is made, for example, someone yesterday advocated the idea of an ombudsman. We've heard advice elsewhere that we should consider an Office of Public Advocate to oversee the scheme and to be a mechanism for people to view complaints. Some people have referred us to the community visitor scheme in Victoria, other people have raised the issue of review arrangements, tribunals, open and numbered complaints mechanisms, annual reports and so on.

So given your interest in advocacy and rights, I was wondering which of these sorts of areas do you see particular merit in, is there a model that you favour more than others? Would you be able to talk about that?

MR BLEASDALE (PWD):   I can hypothesise about it, it's not something that I think we as a sector have actually spent a lot of time thinking about. I think we've been spending most of our energy up to now to actually trying get the service system correct but also addressing, I think, some of the broader systems issues. I think we would be negligent if we went through this process without taking a long hard look at the way that disability services are administered at the state and federal level. I think that has to change. I'm shifting it across there for the moment just to point out that one of the things that we mentioned in our submission is that we do favour the new scheme to be a nationally-administered scheme through probably something like a statutory body which obviously - we have the tyranny of distance here in Australia - would have to have a fairly large number of local offices to be able to practically administer those funds and have a reference point for the scheme.

I would expect and, again, I can't really talk very much about it because we haven't developed it very far, but I would imagine that within this new scheme there would have to be some accountability and other mechanisms and safeguards. Just to pick up your idea though because it's the first time I'm hearing it to be honest about the idea of the public advocate. I'd heard about that notion in a different context which was how were we going to fund advocacy into the future and how are we going to safeguard advocacy. I don't think I've got very much to say from international experience about how well advocacy is funded in other jurisdictions. I don't think it's well funded anywhere, to be honest. So I don't think we can grasp on any particular models from overseas, we have to really make it up for ourselves.

But there's a real concern generally with the current context and also about how we move forward and guarantee proper funding and I think advocacy is one of the ways to safeguard - you know, access to that sort of thing is going to be one way to safeguard these arrangements for people with disability. But there may be certainly a role for public advocates offices in the various states and territories to take on a much greater role in actually funding and administering advocacy so it becomes very much a separate part of the system.

MS SCOTT: Maybe then if you're comfortable talking about the service system maybe we could then direct our questions and comments and your comments in that area. Would that be a useful part of our time together?

MR BLEASDALE (PWD):   Sure, that's fine.

MS SCOTT: You've talked about an nationally-administered scheme. What role do you see being played, if any, by existing state services?

MR BLEASDALE (PWD): I think the current state departments would no longer have the same level of responsibility for individual outcomes. It's something that I don't think they've discharged very well anyway and it gets us away from this dialogue about their reporting on or they're providing only in terms of service outputs and the amount of dollars they're putting into services. I would see them as having a role in staff redeployment in local offices that would have to be based within their state and territory jurisdictions. I would see their role possibly being one of maintaining and enhancing the quality of the services that are on the ground, the specialist disability services on the ground.

There is a bit of a debate going on at the moment about accreditation and quality assurance. We still favour quality assurance focusing mainly on outcomes for individuals with disability so a lot of that data or evidence, if you like, would be gathered through the scheme itself but there is still probably a role to play in making sure that services are accredited in the local states and territories, so I would imagine there may be a role for state departments to play in that.

MR WALSH: Michael, do you see a big change in the service system and at the moment we have in New South Wales some fairly large service providers that have been in operation for a very long time and some smaller ones but not so many really. Do you see a big change in the service system and the way in which services are provided?

MR BLEASDALE (PWD): I think the most fundamental change is that services will have to become much more responsive to individual need and much more accountable back to the individual. I can't really think through whether that means there's going to be a breakdown in the size of services or whether large services have the capacity to deliver things on a very flexible basis. There's much more of a focus back onto the person rather than an endless focus back onto accountability up to the state department. I think there's too much distance really between the people in the top jobs and the people who are actually receiving the service.

But I'm not sure it's going to have the same effect as was anticipated when the Disability Services Act in 1986 came out and suddenly the funding model there acted against really the ability for large service organisations to maintain their administrative infrastructures. I'm not sure that's necessarily a consequence of this but there will be much more a sense of standing or falling on your ability to actually meet those needs and to be able to withstand the capacity for what are now paying customers to actually take their business elsewhere. I think over the past 20 years a number of services have been able to take on board some of that spirit in the way that they've innovated and they've competitively tendered for pilot projects. But whether or not all services have the capacity to be as flexible, I don't know.

MR WALSH: Do you have a view on what are the critical shortcomings in the service provision which may mean the current funding system? What are the early wins that we should be looking at in the system?

MR BLEASDALE (PWD): Having said early on that I waned to talk more about the service system, I think there really needs to be a lot of focus on the difficulty we have in the administrative side of this. There's all the kinds of portfolio and departmental divides. This system has to become much more inclusive. I think you probably heard people talking about the eligibility of the system. We put in our submission that it needs to be much more broad, it needs to adopt some of the characteristics of the international classification of disability functioning, ICF-10, which focus on activity limitations, participation restrictions and also takes account of the person's context. That then includes in a lot of people who currently are excluded from the disability system and who are currently - and I'll take the example of people with psychosocial disability who are supposedly catered for within the health system federally and at the state level.

We're going to have to overcome that, we're going to have to unbundle that and I think because of the way that these bureaucracies have developed over years and the kinds of practices they're accustomed to. I think that's one of the fundamental challenges that if we miss we're not going to get the change that we need in the system, so I think that's one level we really need to look at. One reason that we are suggesting a national scheme is that we think there's just too much argy-bargy at the political level between the states and the Commonwealth around money and there seems to be very little consideration about the states and territories in meeting their totality, their obligation to meet the totality of need within their jurisdictions in that model. We need a system that actually has oversight nationally and is achieving national goals or working towards the achievement of national goals around a significant proportion of its population, ie, citizens with disability.

I'm just stating really fundamental problems, those are political problems, they're problems of the way that state and Commonwealth bureaucracies are divided up, all the demarcation that goes on there and I suppose in sector we're going to address those issues in our submissions but clearly it's going to take a lot of political will for those sorts of problems to be overcome. When we look at the service system itself I think it's probably a symptom really of those demarcation divides. To give an example we have in New South Wales a very successfully run housing accommodation support initiative for people who have mental health problems. That's administered under the Department of Health. I've been around disability services all of my professional life and it looks and smells like a disability-type service to me, yet it's administered in a completely different way, has a completely different set of legislative and standard requirements of those sorts of things. It's a nonsense. So getting some standardisation across the country is one of the major goals of the scheme.

MR WALSH: It would be interesting in your submission if you address that issue of particularly that HASI scheme that I think you're talking about - - -

MR BLEASDALE (PWD): Yes.

MR WALSH: - - - the links between mental illness and psychiatric disability and where they should fit on the spectrum of support needs. When I ask about the most pressing issues in respect to support, I meant from the point of view of people with disabilities. Where are people missing out the most at the moment?

MR BLEASDALE (PWD): I don't feel as if I'm in a position to talk about anything empirically about where service gaps are, I would just be restating what other people have stated, the evidence to date is that there is a growing amount of unmet need. The more money we have put into the current disability service system the more demand for services seems to increase and I think that's one of the reasons why have to look at funding our supports in a totally different way if we're actually going to put more trust, I suppose, into people with disability to be able to determine what their need and what they want to achieve and how best to achieve that with the resources that then become available to them directly.

I think we will get away from this notion which I think persists to some extent at the moment that getting into a service is an end in itself. Getting access to a service is what people aspire to and, therefore, that's one of the demotivators for services to actually be providing what people require. I sound like I'm denigrating services here, I'm not. I recognise that even within this framework there is the capacity to be very innovative and actually support people towards their goals of inclusion and participation. But I think there needs to be a stronger dynamic so those kinds of practices can become more the norm rather than the exception.

In terms of need I would probably have to say that we still are struggling to address the needs of those people who still remain in large congruent care settings, they seem to have largely been forgotten and we seem to be moving towards remedies that just perpetuate the idea that it's okay for people to live in large congruent care settings. There are large numbers of people who are living in licensed boarding houses in some states. The level of support and the expectation of the level of support that we have for them is way too low. There are also people who are not even hitting the system at the moment who are unlicensed boarding houses and people who are otherwise marginalised.

There is a huge need for us to get serious about helping Aboriginal communities to understand disability and to identify what kind of support would be needed and appropriate in those communities and not just leaving it be and hoping it's all going to be all right. I am aware through my conversations with colleagues about the level of unmet need that still persists within groups of people with disabilities from culturally and linguistically diverse backgrounds. I suppose collectively there you've got a large number and if you look state by state and territory you'd see disparities of resources that are applying to each and that's one of the things that we've really got to address in the new scheme. There has to be consistency in amount and quality of support that's available to people, so people have the same opportunities as others to actually move from one place to another as well.

MS SCOTT: We'd be interested in hearing further your views on how much accommodation support is attached to the package that you're advocating that people receive given the disparity in the community and the different needs and desires of people. How would you expect accommodation and housing services to be treated? Could you talk about that now.

MR BLEASDALE (PWD): I can but it's rather off the top of my head. I tend not to talk about accommodation, I talk about housing and I think one of the fundamental problems we have in Australia is that there isn't adequate housing or accessible housing for people with disability and a range of diverse needs. We're only beginning to address that really at the broader level and some of the solutions that we've tried to find rather clumsily through the disability services system has been in recognition of the fact that housing in the way that you or I would expect housing to be available is simply not available to people with disability, so there is a significant problem in terms of the provision of housing.

I like the idea of a separation of housing and support and again this is one of the fundamental issues that has to be addressed at the very, very broad level. It goes outside really even the scope of this scheme but it means that there has to be some negotiation between any new system and existing housing schemes. In Western Australia they made the decision back in 1986 that they would be separating their housing and their support system because they believed that that was what the Disability Services Act actually required them to do. So they've had a much lengthier and a much more mature and robust negotiation between your housing department and your disability service department where the housing department is much more responsive to the particular needs of those.

I think we rush into solving the housing problem through the support systems we run into problems of economies of scale and bringing into existence yet again these congruent care models which are all about purpose-built housing and making sure people have adequate support through the provision of staff 24 hours a day. In an individually-funded system you find people who have moved from those settings, people who have significant ongoing medical needs as well as disability being successful accommodated in their housing of whatever kind, usually of social housing kind or maybe even something they've had the opportunity to purchase if they have those means with this support applied at the same level of funding as they were gaining if they were in high-level support.

When I think of the problem of accommodation and support I still go back to the basics of funding the individual to find the housing: is the housing going to be available? What adaptations can we make to the housing? What kind of agreements can we have with housing departments? What are the kinds of things that need to be done systemically at a broader political level to ensure that from here on housing is provided that's going to be available and accessible to people with disability.

MS SCOTT: Yesterday a number of people presented arguments to us along the lines that by having the individual or, in some circumstances, the family and carers support network in care of the funds would ensure that people receive the services they most wanted or valued and I think you've made a similar point this morning and I think that works in many areas. I'm interested in whether it's going to work effectively in the housing market when we already have acute shortages and people come with special needs and special requirements and much of the housing stock is not suited to that. You're suggesting there may be a solution with social housing. It seems to me whereas you thought this would be demand-driven responses on the service side, I'm just questioning whether there can be a demand-driven response on the housing and accommodation side. Would you like to make a comment back on that?

MR BLEASDALE (PWD): It's worth raising that point. I guess we just have to stick to those areas that we feel we have some ability to make some informed comment on. I don't feel as if I'm qualified really to comment on the parlous state of housing availability in Australia which is what you're quite rightly referring to. I don't disagree with that at all. I just note that when there was a fairly concerted effort in the United Kingdom around the policy of social inclusion, that was really when the social housing organisation stepped up and became much more the provider of choice for people with disability and they're the ones who took on board the responsibility of getting the housing stock, modifying and also, to some extent, brokering relationships with appropriate service providers. Again, the HASI program here in New South Wales is an example of some cooperation there.

I am kind of reluctant to give it away as an aspiration and I think this system should be fundamentally focusing on the delivery of support and services. I accept that if the housing isn't available we'll have to come up with some solutions at that time but I don't think we should then move away from our extremely strong advocacy on saying, "Well, we've got the support in place, what are we doing about the housing." I think the government has a responsibility under its obligations to the CRPD to providing that housing. Now, I don't see this system necessarily as being the conduit for providing that housing; I think it has to fall to other areas of government and other areas of private practice within the community to do so. Other jurisdictions have made that choice to ensure that all new housing meets certain accessibility standards. We're moving very slowly towards that but I think there's more that can be done in that area.

MS SCOTT: Maybe for further reflection after you've had a chance to further consider the issue and consult, it is within our terms of reference that accommodation, not necessarily housing - it's always interesting to think about the distinction between the two - is one of the coordinated support options available. I think you're saying that it shouldn't be there, but maybe you can reflect a bit further on that. Michael, thank you very much for coming forward to day and thank you for providing your evidence.

MS SCOTT: We now have National Disability and Carer Alliance presenting evidence. Good morning. For the record please, could you each state your name. I understand you have an opening statement and then we might ask some questions and have a discussion.

MS HUGHES (NDCA): Good morning, I'm Joan Hughes.

MS WEBSTER (NDCA): Good morning, I'm Pam Webster.

MR BAKER (NDCA): Ken Baker.

MS DEANE (NDCA): Kirsten Deane.

MS HALL (NDCA): Lesley Hall.

MS SCOTT: Thank you.

MS DEANE (NDCA): We just thought we'd say for the record who we were and why we're interested in appearing today. The National Disability and Carer Alliance was formed last year by three organisations, Carers Australia, the Australian Federation of Disability Organisations and National Disability Services with the idea that we wanted to provide a very strong, collective and united voice to pursue the kinds of structural and systemic changes we thought needed to be made to improve the lives of people with a disability and their families and carers in this country.

We were delighted to see in the issues paper that the commission accepts that the current system is broken and we think that's a very important acknowledgment to be made, and the commission clearly takes very seriously developing a blueprint for the future and as a result, you've asked some very detailed and very thorough questions in the issues paper. What the alliance would like to contribute to the discussion is to take a step back and look at the principles which we think should underpin the system. The reason that we think that developing and identifying the principles is so important is that we believe that they're the foundations on which the scheme should be built and that it also provides a mechanism for when you're considering some very difficult details and some of the issues that need to be addressed, the principles provide a framework from which you can make your decisions. So it's a mechanism by which the scheme can be tested, "Should we make this decision? Should we make that decision? Well, here are the principles. Which of these decisions means that the principles which underpin the scheme will be met?" That's why the alliance very much wanted to focus on looking at the principles.

We believe that the principle which should underpin the scheme, first and foremost, is that the scheme should be a mechanism by which the rights outlined underneath the UN Convention should be realised. We believe the scheme should also be based on an entitlement, self-determination, efficiency and effectiveness, equity and finally sustainability. So they are the principles that we would like to talk about today.

MS SCOTT: Good, thank you. Let's pick an easy one like equity. We know, and we've known for some time, that the level of funding in each of the states is quite different, that the services often follow very different approaches. People have pointed to this and have expressed concern that we might harmonise to the lowest level, that it might be a competition to the bottom. Would you like to talk about how you see the equity and the other principles reflected in how the scheme should be designed so that we don't get a competition to the bottom? How much variation in outcomes would you be comfortable with if you would like to encourage innovation and different approaches and so on?

MS HALL (NDCA): I'll start. I guess in terms of equity, the scheme has to be whatever anyone needs, they get. At present, the schemes aren't based on that principle and I think particularly with things such as motor accident schemes et cetera that differ from state to state, some of them are based on no fault and some of them are based on fault. But basically in terms of equity, if you need support because you have a disability, you should be able to get that support no matter where you live in Australia.

Now, that's the fundamental principle. That will be different for every person in terms of their cultural lifestyle, in terms of their family situation, in terms of where they live. So particularly when people are in different living situations which there will be many times where people will be living in situations where a different approach is going to be necessary and particularly, as Michael mentioned before, in terms of Aboriginal communities, certainly there will need to be different approaches, innovative approaches. That's the same for a lot of people with disabilities, that you have to have a scheme that actually meets the individual's wants. So there are times when the support system that will be available won't meet the needs of those persons. Therefore, there does need to be innovative approaches made for that. So it's a fundamental aspect of the scheme that it needs to be flexible enough that if people require innovative support, then the scheme needs to be able to assist in developing those and sustaining those.

MS SCOTT: If you don't mind, I wouldn't mind teasing out a few things, a bit like a hypothetical, for a while, just to see how we go. So, for example, we know that in some states there are very limited housing options available, very limited accommodation options available, and in other places, other states, they have already allocated a certain proportion of public housing, providing accommodation and housing for people with disabilities. So housing stock and housing availability varies very considerably from market to market, from Darwin to Sydney to Perth and so on. If it turns out that someone is having difficulty entering the housing market, would you like to see housing, either supported accommodation or non-supported accommodation, as part of the scheme?

MS HALL (NDCA): I think that's a question that perhaps our individual organisations may respond to differently, but I think certainly our combined response would be that whatever the person needs they should be able to get.

MS SCOTT: So just imagine someone in WA may not need a housing package because effectively they can get it from public housing, but in New South Wales they may well require a housing element to it. You're getting quite different outcomes for an individual who may have the same broad assessment.

MS HALL (NDCA): I think one of the fundamental principles is that this scheme cannot act in isolation. It has to be absolutely embedded in the UN convention, but it also has to recognise that there's a whole lot of other changes that need to be made within Australian society for it to be effective.

MS SCOTT: That's fine; I've got that. So, Lesley, I'll park that question, then, about different housing packages because I think you've indicated that the different groups may have a different view. What about your view on whether the existing accident compensation schemes should be incorporated into the scheme, or should they be allowed to continue as they are, varying from state to state, from period of time to period of time as in New South Wales?

MS DEANE (NDCA): I think that's a good question where again we can refer to the principle of equity. So the idea that the current system is inequitable; that you can receive a certain level of support through TAC but not if you acquire your disability in another means. Again, our position would be you road-test that idea of equity and say, "Can you achieve equity by having the two schemes in coexistence or do they all need to be rolled into one?" So the question is always about how do you achieve these fundamental principles that we're asking about.

MS SCOTT: What if you came to the view that because of - we've got a variety of schemes around Australia - the very high cost associated with some particular schemes that if that was to be offered everywhere to every person that may not be affordable, would you then favour a system where those at the top had less available to them in order to have more available to everyone, if you understand what I'm saying?

MS DEANE (NDCA): No.

MS HUGHES (NDCA): No. We would be very clear about that because I think one of the terms of reference that you're looking at and wanting to make recommendations to the federal government about are the linkages across the different systems.

MS SCOTT: That's right.

MS HUGHES (NDCA): I think we've got to be clear that if we get the principles right and you can measure those across those different systems, you might get a different mix in the states and territories. From a family carer's point of view, what we know now is that still most of the care is provided by families and carers, and is that right? Well, obviously in some circumstances, yes. Is that the society that we want? Yes, we do, but we can't continue the system where our family carers' own health and wellbeing, I guess, is compromised because of the levels of care that have to be provided. So I think the important message is around the linkages of the different systems and that's very complex.

If you're going to look at the housing, the housing stock, if you're looking at the linkages across health, across aged care, mental health and so on, and I'm sure you're hearing those messages that, "We want this scheme to be able to address those issues that are of things to do with inequity; people not being able to access really basic supports, and we want it for all people," because investment will actually save governments in the long run.

MS SCOTT: One last question and then I'll hand over to John. I'm sorry to put this difficult question to you but it's just the reality that some people we've heard from should be getting five days of assistance and they're getting two days, some people are assessed as needing 36 hours and they're getting two hours, they're getting two showers a week; vastly different gaps between assessed need and actual provision of services. On the other hand, in some states, in some jurisdictions, just by the fortune of where they are in terms of their particular suburb, some people are getting the 36 hours of care they need. Some people are also getting individual supported packages in accommodation; they're getting assistance with recreation services and so on. I mean, there are some people who look like they're on a mountain top and other people are in the pit of a valley. Now, is your view that everyone comes up to the mountain top? I just need to know what your version of equity is.

MR BAKER (NDCA): That's not our view. I think our view is that people, as Lesley said, get services and supports appropriate to their assessed need. The perverse incentive in the current system is that because it's a lottery essentially, if people do get ample services, then even if their need happens to diminish they're not going to let go of anything they've got because they're afraid that if their need escalates again they won't get it back. In a system that clearly said that if you're part of the system you have an entitlement, but that entitlement, that package of services, may change as your life stages change, as your circumstances change - and it may diminish at times and it may increase - but if you have that guarantee from the outset that an appropriately assessed need was going to be met through services, then I think you'd be much more willing to let go of what you had if you didn't need it at this moment in time.

MS HALL (NDCA): Just to add to that; if you only need one hour of support a week and that enables you to continue your education, to move into employment, you should be able to get that. If you need - I don't like using the "34 hours" because that's what it's currently pitched at, or 36 hours - but if you need much more support than that, then you should be able to get that. So it goes back to the individual person and they should be assessed as to what they need and that's the support that they should get, and that should be regularly reviewed as circumstances change. There's a whole lot of ways that circumstances can change. For example, a family member may die so there may be extra support that's needed for that.

MS SCOTT: It's also very clear, isn't it, that if someone was living in New South Wales and had a motor accident with a severe brain injury, that their level of assessment would be very different from what the same person in exactly the same circumstances would receive in South Australia and Queensland, and I guess I'm encouraging you to think about what assessed level of need you think we should be applying; the New South Wales scheme, the Victorian model, the South Australian model, some variation of all of them.

MS HALL (NDCA): The assessment scheme that we should be using is an assessment of the individual. So that we're not recommending one particular assessment scheme at the moment because this is additional work that needs to be done. I feel that, as Kirsten said before, in the development of the assessment scheme you need to go back to the basic principles that we've been discussing, but the basic principle is, if you need it, you get it.

MR BAKER (NDCA): Can I just make one point too. I'm a fan of the Productivity Commission's report on government services because I think it does attempt to have comparative measurement of funding levels and performance of governments and so on, but I know that's it been an evolution over time and that there's still a lot of qualifications and reservations about the comparison. So simply looking at the different funding packages that people get around Australia, it's not necessarily a reliable indicator yet; I think that data is improving. I would suggest as part of any new scheme that data collection and indeed benchmarking needs to be part of it. Benchmarking is very important but we have to make sure we're comparing apples with apples.

MS DEANE (NDCA): Could I also say that it's something of a furphy to say that people with a disability and their families are not interested in a sustainable system; pitting them against each other isn't, I don't think, an accurate picture because people with a disability and their families are very interested in having a sustainable system. The current system isn't sustainable and the responsibility for care and support falls back on individuals. So they are very interested in a scheme that is sustainable, and pitching those things as in opposition to each other isn't an accurate reflection of where we believe people's heads are at.

MS SCOTT: Do you think someone had done that?

MS DEANE (NDCA): No. I just wanted to make that clear; that sustainability is something that everybody is interested in.

MS WEBSTER (NDCA): I was just going to say that the other problem is that the services that are provided at the moment are what is actually on offer. For some people they do have a degree of individual choice on what that service is and who will provide that service, but that doesn't happen very often. In fact, often the services that people are given are actually not exactly what they would prefer, it's what is available at the time, and they take that, as Ken said, as part of, "I'll take something rather than nothing," but it may not actually meet their needs.

MR WALSH: I've got a couple of questions. First of all, Lesley, you're talking about this scheme being whatever a person needs, they get, and that seems to be a fundamental premise that you're putting forward. I guess - and this relates to my second question, which is around the principles - my question is the extent to which what people need they get from whom. Is it all from the formal system or is it a legitimate response, in your view, that families and carers are supported to continue providing some of that support need?

MS HALL (NDCA): I think people with disabilities want to have family life in all its variations; they want to be parents, they want to be included in families, they want to be included in their communities. So basically what we're saying is that families need to be sustained as well as people with disabilities. Also that family members need to be able to make their own choices about what they do with their lives as well, and presently family members aren't able to make those choices. So that if a family member wants to choose to support the person with a disability, that should be able to happen; but if the family member has to give up their work to be able to do that, then that's what we think needs to change.

I mean, obviously families have, in our society, a whole lot of different functions and part of that is a caring function, and particularly families with young children. So we certainly don't want to take away, in terms of the system, encouraging those sorts of roles within families, but where it becomes such that the child has - with a disability there's additional supports that are needed, then we say that that should definitely be part of the system.

MS HUGHES (NDCA): I suppose I need to make a comment, too, on that. I think what we've got to make sure is that through the assessment process that we have a person and family-centred approach to that. If you can get that nationally done and adhere to certain standards around assessment, you will pick up needs of all of those people involved in the disability or in the care situation, and that will change over time. So you want the scheme to actually look at a lifetime approach to whatever the scheme is going to be because needs will change, there will be intense times of caring where families will maybe reduce hours of work but they want to have protection of their work so that they can return to work.

So I think if you take a national approach to assessment and you take a lifetime approach to care and support within this new scheme, you'll get some of those balances addressed. The current situation, as I said, still most of the care, even though we've had increase in services, is done by families and carers. We need to re-address that balance and we've got to make sure that the rights of families, as individuals and as a collective, are picked up in the scheme as well.

MR WALSH: I've got another question before I get to my second question. Just on that one, some of the assessment methods and processes and tools that have been put to us, some of the more sophisticated ones, are needs-based; so, what do you need. They also have components of availability of informal care as part of their assessment. Is that something that you guys are supportive of? Yes. Okay.

MS WEBSTER (NDCA): I think it's really important, though, to make sure that the support and care that's being provided by families is actually at the level that they're happy to actually be able to provide because otherwise the burden of action falls upon - I shouldn't use the word "burden", but families sometimes take on the role of providing more care and support than they might otherwise do if there were adequate supports for the person with a disability.

MR WALSH: I understand. My second question relates to your principles; and thanks for laying them out like that, it's helpful. Have you given much thought to the situations when there are conflict between the principles. So, for example, just looking at it quickly, entitlement versus sustainability, self-determination versus effectiveness and efficiency. Have you thought about the interactions between the principles and, if you haven't, it would be really useful if you could do that in your submission.

MR BAKER (NDCA): Yes. Look, I think it's difficult to do that in the abstract. I understand that in application there will be areas of conflict and overlap and they will clearly need to be resolved on the merits of the particular argument, case or situation, but we'll give thought to that.

MR WALSH: The obvious ones are it would be nice to provide everything but we're probably not going to be able to afford it. So where are the boundaries in each of the principles.

MS WEBSTER (NDCA): That's one of the issues around self-determination, because if people can actually have some input into what services they actually want, they can prioritise them and they may end up using even less services than they currently use now because they actually feel like their needs are being satisfied.

MS HALL (NDCA): I think also that this is why this scheme needs to actually have a very strong interface with the system it changed overall because unless we get a lot of that systemic change the need for continued support will be there. So that we need to make sure that this just does not operate in a vacuum; that it does operate with broad systemic change so that the generic services can pick up what they should be picking up in terms of supporting people with disabilities.

MS DEANE (NDCA): I'd also say that we do intend to provide a more detailed written submission to you, but in our thinking of it and developing it there is perhaps not as much conflict between some of the principles as we might have imagined.

MR WALSH: Good.

MS HALL (NDCA): Particularly in terms of at present we're working a grossly unfunded system where rationing is basically the way that everything happens. Until we are working towards a system where people's needs are met, that really to be able to say that people's needs won't be met or can't be met under our present level of wealth in Australia, I think, is conjecture that we need to be working towards.

MR BAKER (NDCA): The paradox is our current system is highly rationed but it's not particularly efficient and it's not sustainable, whereas if we had a system, for example, that built up a fund over time, that fund could then be used to invest in strategies to reduce longer term need, like social inclusion strategies, early intervention strategies, just as the Transport Accident Commission invests in strategies to reduce incidents of motor accidents and therefore reduces the long-term cost pressures on the scheme. Our current situation, because it's so focused on meeting the current crisis, doesn't act in the long-term interests of anyone.

MS SCOTT: That's good. Could you comment on the service model, a national approach, national standards? How do you see service occurring? I appreciate your point about individualised packages and assessment on need. But do you see the continuation of services through state departments, through state-funded services, through states providing funding to organisations? Could you comment on that, please?

MR BAKER (NDCA): I think there certainly need to be nationally consistent rules and funding models approached. So I would see at least the role of states would be reduced. Whether it would disappear altogether, I don't know. But there are efficiency gains, I would suspect, in reducing the current inconsistency of rules across Australia.

MS HUGHES (NDCA): But the service delivery will have to be done at obviously a local and an individual level. You can have a range of models to do that. What we want to be able to see in the scheme is that there have been savings in reducing some of those inefficiencies. I think if we can build up investment in this scheme, then - to address one of your questions, Patricia - you'll have more opportunity to do research and innovation and development. If people feel like they have more control over their lives it will free up a whole range of different approaches.

I have just come back from some international work. Last time we spoke you were also interested in what is happening internationally. So I'll send you some information of some work that's happening in the United States; they have got a scheme there, of which I'm not sure you're aware, where employers pay into a care scheme. There's also some interesting work happening in Ireland. So, internationally, governments are thinking about some sort of social care insurance models as well. So those two pieces of work might be of use to you as well.

MS SCOTT: Thank you.

MS WEBSTER (NDCA): I'd actually also like to make a comment. I believe very strongly that the disability sector and the aged care sector - there's two inquiries going on at the moment - should be working really closely together in terms of a social insurance model so that in fact this scheme actually goes right across the board. I think that will actually bring efficiencies in a whole range of ways.

For example, at the moment we have disability services and aged care services, and there is absolutely no reason why an aged care service couldn't provide some of the same services that disability services now provide and vice versa so that people in fact could have a wider choice of people who are actually offering the services. From a carer's perspective, if you're a carer of someone with a disability and you're also caring for an aged care person it's really important to be able to have one single service provider provide all the services, because it makes it much more efficient.

MS HALL (NDCA): In terms of what the mix will end up looing like, you need to go back again to the basic principles that we're talking about. No matter where you live in Australia you should be able to get what you need. Certainly in the UK they also have a model of commissioning services. If they see that there's a gap somewhere then they can actually commission a service to actually meet that gap. I think that's an interesting principle at which we could be looking.

But certainly the way that the current system works, where you have three levels of government that actually provide supports with three levels of different ways of administering that support, is very inefficient. Also, with the lack of services, that people will access services a bit here and a bit there to actually cobble together a package of supports, again that's an absolute inefficiency. So the scheme does need to be nationally administered. It needs to have national principles. How that looks on the ground really will depend on the local circumstances of people.

MR WALSH: What do you see the national administration body looking like?

MS HALL (NDCA): We have probably got different views on this. It's not something that we have actually talked about as a group.

MS HUGHES (NDCA): But it's obviously going to have to have a governance role and they're going to have to set the standards around entry and assessment and delivery and review, the sort of normal national governance model that works well - - -

MR WALSH: The fund-holder?

MS HUGHES (NDCA): Who should be the fund-holder? We haven't really made a decision on that. But we will put some ideas into our detailed submission.

MR WALSH: Presumably if it's a collective or social insurance type model, the funds would be pooled somewhere at the start. How those funds are managed and eventually get to the person who is purchasing the services would be a useful thing for comment.

MS HUGHES (NDCA): I think some of the models that work particularly well in the community are round brokerage models, and I think that could be another model that we'll discuss a bit more in our submission too.

MS SCOTT: It's a general theme that we're keen to explore with everyone, how broad concepts or principles can get operationalised and get to the design. I know these are very difficult questions, but we'd certainly welcome your contributions on that. Thank you very much for attending today. We now have a morning tea break. There's tea and coffee in the room next door. There are toilets at the end of the corridor. If anyone needs any assistance, please indicate. We'll come back at 11.20 to resume the hearings. Thank you.

MS SCOTT: Welcome back to our public hearings. I welcome to the table Fiona and Phillip. Could you indicate the name of your organisation and then make some opening remarks.

MR FRENCH (NSW DDLC): We're appearing on behalf of the Disability Discrimination Legal Centre.

MS GIVEN (NSW DDLC): Thank you for hearing our evidence this morning. The New South Wales Disability Discrimination Legal Centre is a specialist community legal centre which provides advice and casework to people with disabilities and their associates on disability discrimination issues. We also contribute to policy and law reform relating to disability discrimination and broad human rights issues pertaining to people with disability.

Any scheme created by the findings of the Productivity Commission must comply with the United Nations Convention on the Rights of Persons with Disabilities. Specifically, we would like to draw your attention to article 3 which outlines the general principles of the convention and article 4 which outlines the general obligations of state parties. Article 4.1 requires state parties to undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.

The scheme must be funded primarily by a dedicated tax. This tax could be along the lines of the Medicare levy, the rationale for a dedicated tax is twofold. Firstly, it specifically quarantines a specific amount of money for a disability scheme. Secondly, it informs taxpayers as to where their taxes are going as well as generating awareness of disability. Over time the scheme must also incorporate private insurance arrangements such as motor accident insurance schemes. The scheme ought to be national. It ought to finance and manage all present Commonwealth, state and territory investments and supports for persons with disability. It ought to provide for absolute portability of payments, equipment and services across Australia.

The scheme must be fully funded. The levy must be calibrated so as to ensure that it is able to provide an appropriate level of funding and supports for all individuals currently in receipt of support as well as those who ought to be able to obtain such assistance but currently cannot. The funding base for the scheme must enable the realisation of all human rights, not nearly subsistence. The scheme ought to be remedial and constructive. Funding must be calculated so as to enable the immediate reform of those elements of the disability support system that do not conform.

With human rights principles in particular to eliminate institutional models of service it must also enable the development of new elements of the disability support system where needed programs and services do not presently exist. The scheme must be entitlement based. The scheme must not be subject to any form of means test. Eligible persons ought be entitled to assistance as a right and receive assistance at the point of qualification. They should not face the delays and compromises associated with cash-start discretionary schemes.

The target group for the scheme ought to be all persons with impairment who are disabled, able to specifically include persons with psychosocial impairment. The scheme also must not be limited to people classified as having severe or profound disability as proposed by your initial brief; instead we argue that it should be based on the need to have support in order to realise rights articulated under the CRPD. This effectively views disability through the lens of the social model of disability which looks at how the social environment disables a person, as opposed to the medical model which looks at the impairment.

MR FRENCH (NSW DDLC): So that's the conclusion of Fiona's opening remarks and I might just highlight some other points from our submission and then we'll be guided by you as how you like us to give our evidence from then on. So some other points that we just wanted to flag; that we believe that the scheme must be used for self-directed funding and I think you've heard enough evidence about that for me not to elaborate further on that at this point. One thing that perhaps hasn't been discussed a great deal is how the scheme portrays people with disability and we say that it's very important that the scheme portray people with disability in a positive light and assist in combating stereotypes and prejudice.

In this respect we want to point out that the language of insurance and the nomenclature that's been used to date does have, inherent within it, certain risks in terms of the public portrayal of persons with disability. Insurance, in the public mind anyway, can lead people to conclude that there are risks to be eliminated and sometimes that can equate with the elimination of persons with disability as opposed to disabling environments, which we think should be the focus of the scheme. So one possibility for more positive nomenclature is to use words that are already in use for some schemes in Australia and which are widely in use at the international level.

For example, we might have the levy called the Enabling Australia levy which would positively socialise the public towards something that would enable the participation of persons with disability. The agency that we propose would administer the scheme might be called, for example, Enable Australia. So this would, I think, put a very positive accent on what the scheme could achieve. Even though its underlying structure of course would be a social insurance model but it would position the scheme in a way that we think would positively socialise people with disability and positively socialise the public to what this scheme is attempting to achieve.

We think the governing body or the governance structure of this scheme should be comprised by a majority of persons with disability. We want to be clear, though, that when we talk about the governance body we're talking about the strategic policy monitoring and evaluation functions; we're not talking about the distributive or service delivery functions which we think it's essential be provided by government. We don't want to get into the ATSIC problem of where a specialist agency had all of the responsibility and it ended up being blamed for everything that happened. We think it's much better that the governance body be responsible for the strategic policy and the outcomes that are produced - for evaluating those, I mean - and that government itself be responsible for the distributive elements and the service delivery elements within the system and, of course, it might enter into partnerships with the private sector or non-government agencies in order to do that, but it would be responsible for those aspects of the scheme.

We also think that it's important that in association with this scheme there is an independent merits review process established which would allow people to contest decisions that they think are unfair as to eligibility or quantum of assistance that they receive. There would also need to be a robust independent complaints body in place so that people would have genuine redress for grievances about service quality issues and so forth. We think there should be an independent quality assurance system. Finally, we make the point that though in all other respects we think the services available under the scheme should be capable of being purchased through self-directed funding packages. There are some other supports that really should be provided structurally, like a national disability advocacy program. We wouldn't see that as something that it's appropriate to fund out of individual support packages; that seems to us to be something that should be funded as a structural element in a safe and robust system. So they're our initial comments.

MR WALSH: Thanks, Fiona and Phillip. I have one question which is potentially a bit of a difficult question and that is that in a couple of places you talk against group homes and institutional care. We've heard from some people that congregate housing of some sort might be the preferred option of some people with disability and I just wonder if you have any response to that.

MR FRENCH (NSW DDLC): Well, the overall framework that we believe the scheme must be created within is that provided by the United Nations Convention on the Rights of Persons with Disabilities and in this instance Article 19 speaks specifically to the sorts of support arrangements that ought to be provided as a matter of public policy. There are all sorts of reasons, historical reasons and some contemporary reasons, why people might think that they would receive better forms of support in institutional models of care, but the research evidence, quite apart from the human rights issues involved, is overwhelming that institutional models of care produce very poor outcomes for individuals. So we wouldn't see that as being something that it's appropriate to offer as a matter of public policy.

MR WALSH: Just extending the same point. Would you have a problem with accommodation models which are effectively shared support type accommodation models? One example that's been put to us is where there's a block of units and half a dozen of those units might be provided to people with disabilities, and within that block of units there's a resident almost caretaker, carer of last resort type person, that would allow those people to live independently.

MR FRENCH (NSW DDLC):   Well, it would very much depend on the structure of that. If people are being required to live in such an environment as a condition precedent to receiving any support, then we wouldn't think that that would be something that should be permissible. Given what Article 9 of the CRPD requires, if we're talking about people who have control over their supports and funding choosing to live with each other because they like each other and think that they can get something better by sharing accommodation and supports together, then that's really a matter for them rather than for public policy. What often is presented as people's choice is governments offering congregate settings where you either take the support that's available there or you take nothing, and then that's presented as a choice on the spectrum.

It's also often the case that it's family members and carers who are making a decision to institutionalise their son or daughter or family member because they think that's all the person is capable of; and we say, as a matter of public policy, government should assert the inherent dignity and rights of persons with disability to live in and be a part of the community, and therefore government should engage as constructively as possible with families and carers to combat the attitudes and beliefs that underpin decisions that ultimately devalue the dignity of people with disability.

MR WALSH: So am I correct in interpreting what you're saying as that the important issue here is that the person with the disability has some choice in the situation in which they live?

MR FRENCH (NSW DDLC):   Yes, but there would be one footnote to that, in that often what is presented as choice is not real choice at all. For example, if we're looking at New South Wales at the moment we have a massive rollout of what is really a program of reinstitutionalisation of people and the public face of that uses the language of choice, and really there is no choice underpinning that policy. People are being forced to live in new institutional environments.

So language can be quite tricky in this area. If people have control over their own supports and funding and if they choose to live with other people in order to pool supports to get a better outcome, or if they want to share with other people for friendship and socialisation purposes, then we wouldn't object to that. But we would object to any form of public policy which compelled or obliged people to live together in order to receive support services.

MS GIVEN (NSW DDLC): I just want to emphasise that often families choose that for their family member with disability because it is perceived as the safe option. When it is the opposite, people are more likely to be abused in congregate care situations.

MS SCOTT: Can I just explore this just a little bit more? When does bringing people together form an institution? Is it four people, six, eight, 30, 50, 100? Do you have a view on that?

MS GIVEN (NSW DDLC): I say that numbers don't matter. You can be institutionalised in your own home. It is the manner in which services are delivered.

MR FRENCH (NSW DDLC): Yes, I'd agree with that and add to it that really the situation is a person becomes institutionalised when they're forced to conform to an externalised system of management, like routines that say that you can only have your meal at 5.30 in the afternoon, if you want to have a personal care that that's only available at 6 pm, and basically you can't run your own life. So the bigger the system perhaps the more acute the institutionalisation. In a group home where five people live where all those five people are subordinated to an external system of control that might be offered by the disability support provider is every bit as institutionalised in that sense.

What we think a national scheme should do is provide for people to have control over their own lives and routines; and if as part of that they might choose to live with one or more other people with disability then that's entirely a matter for them, but they're in control of their own services and supports, including what time they get up, who they socialise with, when they have their meal, when they have their shower, those sorts of things. That's what institutionalisation means.

MR WALSH: Do you have a view or have you thought about the way in which a support systems to provide that flexibility might be constructed?

MR FRENCH (NSW DDLC): We think a mixed model is very important. The fundamental element should be that people should receive direct funding for their supports and then there should be an array of services that are offered either by mainstream service providers or by specialist service providers from whom they can contract the services that they need. You know, one of the big problems in the disability services area has been that it is really a closed market where there are very high cost options driven up by scarcity, and a mixed model of support I think would help drive costs down in areas where there is market demand.

Looking at the area of domestic assistance, for example, that's relatively costly when provided in the specialist service system. I'm not an economist, by any means, but my basis understanding of the issue is that many commercial providers can provide just as good, if not better, domestic assistance services to people than the various home care authorities around the place, and if they can provide a better quality of service that provides better flexibility and control for individuals then they should be entitled into this market.

Having said that, there will be some specialist disability supports where really there is no substantial market - for example, the provision of Auslan interpreter services - and there will need to be a specific specialist measure I think in order to meet that sort of demand. So a mixed model that takes advantage of what the open market can provide as well as what the specialist market can provide. But I think the overall aim progressively would be to residualise as far as possible the specialist services component, because ultimately it's a parallel system that is very expensive and far from providing better quality services it ends up providing less preferred services.

MR WALSH: Could I just ask one more question. With respect to this flexible market, do you have a view that the provision of support services such as personal care can only be provided by people who have some sort of accreditation or certification, or is it legitimate for the person who is directing the funding to purchase those services from a neighbour or a friend?

MR FRENCH (DDLC):   It's actually a hard question for us, and the reason it's a hard question for us is because there's a history of professionals taking over the lives of people with disability, and so many of the people that we are associated with would be concerned by the professionalisation of the disability workforce because they would see that as another way of people in white coats taking over control of the basic issues in their lives. That's on the one hand.

On the other hand, if someone is performing a bowel evacuation, for example, that presents a very significant risk of harm to the individual if provided in an unsafe and unsanitary way. We would say there ought be basic standards with which that person is required to comply. The ultimate solution may be some kind of tiered approach, where people who require things like tracheostomy changes and bowel evacuation and those sorts of things where there are assurances around the sorts of interventions that are provided there and the people who provide them would choose that, whereas people who require basically a pair of hands might be able to choose from a wider spectrum of potential support workers. I might just check whether Fiona wants to add anything to that.

MS GIVEN (NSW DDLC): Yes.

MR WALSH: Fiona, while you're drafting your answer, if there is that hierarchy or tiered notion, who has the choice as to where along that continuum they purchase their support needs? So it's a risk-taking question.

MS GIVEN (NSW DDLC): It is tricky. I currently employ university student care staff, but there is a high turnover and significant knowledge gaps. In particular, they can't see dust on the floor.

MR FRENCH (NSW DDLC): Have you finished? If I may add to that, one part of the answer might be, in terms of the accreditation of the staff member for the services that they're entitled to provide, there is a model at the moment being proposed for the development of a model of disability professional, and a lot of other professions are regulated as to what they may do. So an enrolled nurse, for example - I'm sorry to use a medical model, but it's just convenient - an enrolled nurse may do certain things, whereas a registered nurse is entitled to do some other things.

It may be if we move to a tiered system of disability support worker there might be a generalist worker who is capable of doing some things but there might be specialist workers who are entitled to do a different category of things, for example upper bowel care and tracheostomy support and those sorts of things. On the issue of who gets to choose, I'm the sort of person who thinks that people should be able to make their own choices about these things, but I'd turn the question the other way. As a matter of public policy, it's up to government to agree what it will do.

So people might make all sorts of private choices, but the question really I think for the commission is, "For what should government pay?" Again to use an analogy here that comes from the medical model, if you look at the current controversy about home-based midwifery for example, women should be free to choose what sort of home birth they want, but in terms of government responsibility, to ensure that all birth is safe and that appropriate practitioners are involved in home birth, they regulate that profession.

It's slightly turning your question on its ear, but I think that's the real question, "In what, from a public policy perspective, should government be investing money?" and I don't think it's appropriate for government to be investing in things that are unsafe. Whether people make private choices about that is ultimately a matter for them, subject to certain constraints, but in developing a disability support system government should only be investing in things that are safe and appropriate for individuals.

MS SCOTT: Thank you very much, Phillip. Thank you, Fiona.

MS SCOTT: I now call to the table Adam Johnston. Welcome, Adam. Could you state your name, and I think you're representing yourself. Is that correct?

MR JOHNSTON: Yes, that's correct. Adam Johnston is my name. I appear here as a private citizen who has provided you with a submission.

MS SCOTT: Thank you.

MR JOHNSTON: In opening I would say from what I've heard this morning that there are some elements of prior witness testimony with which I agree. There are some issues that I have certainly raised in my submission, that I hope we come to when it comes to questions, that I have concerns about. Certainly it appears to be assumed throughout this inquiry that there will be some form of what is generally called national disability insurance, some form of scheme, and that it will be funded by Medicare or a Medicare-type model.

As I have highlighted in my submission, several senior economists, most notably Geoff Carmody, formerly of Access Economics, has highlighted that that is a regressive tax which hits the lowest income earners in our society at an effective rate of about 35 per cent. This should be a concern, because this commission should not just consider disability policy but the effects on the wider community, for a number of reasons.

First of all, we're talking here about inclusion, yet we're asking the rest of Australian society to pay a new tax and we are potentially asking those on the lowest incomes to pay a much higher rate of tax. This should be a concern to people individually and generally because as a disabled person dealing with people who are not disabled on a daily basis, one thing that you rely on is public goodwill. You can't do without public goodwill, and a proposal that requires people to pay a significant increase in tax, be it effective or real, puts some strain on that public goodwill, which I think is a danger that this commission should be aware of.

Equally the discussion, in my submission, relates to personal circumstances under a new scheme being run by the New South Wales ADAC department, notionally known as "attendant care". Again, this used all the language of choice for me and my family. I would submit that it was another government scheme which had the same rigidity of regulation, guidelines, protocols and assessments which made it indistinguishable from any other government scheme. Equally we should also consider the questions of just how much do we want government to regulate every part of our lives. Certainly there is a high degree of government regulation in everybody's life, but I would want to put it to this commission that if you are a disabled person or somebody else with a need, be it a medical need or some form of social disadvantage, the level of regulation or oversight by one form of government or another is extreme.

I guess the clearest example of that would be policies directed towards Aboriginals. As you would be aware, in the Northern Territory welfare payments can be quarantined if the government determines that a person or family is not spending moneys correctly. Let's just step back a moment and realise what that means. That means that a government department is operating at the individual family or individual person level to determine what they can buy, sell, eat, drink and virtually where they shall live and what standard of living they shall have. We should ask ourselves generally, will this be applied to other people more widely? Certainly there were suggestions that welfare payment quarantining was going to be put on a more general footing and there was legislation passed in the federal parliament, just before Kevin Rudd was no longer prime minister, which the opposition supported to facilitate that to a degree.

Applying that to a disability support scheme, whatever you wish to call it, you do need to ask the question of how much control an unnamed government bureaucrat or bureaucrats will have over an individual family or an individual person with disabilities. Again I would suggest from testimony we've just heard that we should also look at institutionalism from the basis of government and individual. The government can impose what in effect is an institutionalised model by simply the reams of regulation and demands it places on somebody simply to access service. With that, I invite questions.

MS SCOTT: Thank you. Does Geoff Carmody or yourself have a view about what alternative means would be used to fund increased funding for services to people with disabilities?

MR JOHNSTON: I can't speak for Geoff Carmody, I've never met the man. What I'm relying on there is a speech he gave to the National Press Club which is cited in the submission. What he was talking about at that stage was wider taxation reform. He wasn't speaking specifically about this issue. What I would say is that I don't believe the question of funding of people with disabilities should be seen in isolation from wider taxation reform. It is very well known, for example, that there is a great degree of what we shall call "welfare churn". Many people pay taxes only to find them returned to them in some form of rebate or subsidy, be it Family Tax Benefit A, Family Tax Benefit B, the Baby Bonus, or things like that.

Questions really should be asked as to what can we do to modernise the tax system so that people who earn a level of income which means effectively that they will get all their taxes back can be relieved of the necessity to go through a process of paying tax if all they're going to do is get their money in a different form. So that is all about making the taxation system effective so that people who actually earn can keep an effective amount of their earning potential, which should actually encourage more people generally, and I'd say to a certain extent people with disabilities and other people in disadvantaged groups, to actually enter the workforce because they can be made aware that they will actually get to keep a substantial amount of their income. I also acknowledge that a number of people with disability or at least a large part of us would work in situations where we either would have subsidised wages or we would be in the situation of the tax welfare churn.

MS SCOTT: I think you're on the money when it comes to tax welfare churn but I guess it's unfortunately outside our scope of reference. So I guess could I take it that you're advocating greater tax deductibility for those that are in employment who have disabilities and would like to access services or are you after a tax holiday so you can access those services directly out of your increased income?

MR JOHNSTON: Well, to a certain extent I would generally be more supportive of the latter purely on the basis that it involves less red tape. Another thing that I think we have to be conscious of is that a lot of the assessment models, a lot of the criteria that are applied before somebody even gets into a program of support, whatever it is for, goes to administrators who don't actually deliver any support. You'll notice in my submission that I try to simplify a system down to what I've called a minder model where an individual person finds another person who is prepared to take care of them. Under my ideal thinking maybe the second person lives with them and the exchange is a very free, individual contract. It's not even necessarily monetary based. They may exchange on the basis of board or food and, "In exchange for a place to live you will take care of me," or other such things like that.

So it's simplifying the system. It's as much as possible getting governments out of the way, which is a theme I come back to in my submission. Again I might also raise for your attention I am aware of a Canada-based model; it's called Plan Canada, and that was a group of parents who got together and decided to look at the issues about how they were going to support the needs of their children as they aged and as their parents aged and unfortunately passed away. One rule they made or one undertaking they gave is that they were never going to take one dollar of government subsidy.

The director or the chairman of the organisation came out to Sydney a couple of years ago and he presented at the state parliament. He said, "The moment you take a dollar from the government you end up with all these rules and problems and red tape, and that increases the difficulty for your organisation and it requires you to hire any number of other people who don't provide services to simply manage relations with the government."

MS SCOTT: Just on that, you favour a tax reduction or deduction for those in employment. What would you advocate for those that don't have an income, are reliant on the welfare system? How would services be funded for those people?

MR JOHNSTON: I think that gets back to the wider question of tax reform because, again, even those on welfare can be in a situation, for example, where they might work in what - I'm not sure what the current terminology is, but what would generally be known as a sheltered workshop. What happens there is their wages are pegged to an actual pension. So there are some people who are actually kept on some form of welfare but they're also doing some form of work. I think we have to ask the question of if we were to reduce or take certain people on lower incomes out of the tax system all together, how much could their income rise so that they were better able, maybe individually or collectively, to take care of themselves? Now, I'm not saying that government would be completely out of the process. There would still be a welfare system but I think the first question needs to be, how much, again, does the government need to keep the tax and transfer model up?

MS SCOTT: The Plan Canada, you indicated that it didn't take a dollar of subsidy. Did they take a dollar of tax deductions?

MR JOHNSTON: Probably they did. They probably rely to some extent on deductions, and from the address given there was certainly contributions from families which provided some of the seed capital for the organisation as well. So I don't deny for a moment that that will necessarily cover everybody's needs. I guess what one of my central messages for the commission is, the one thing I don't want to see is more government control. I, myself, in all the care arrangements I might have, seem to, at one point or another, have to deal with government. Again, even when it comes to accreditation, I've also highlighted a point there in my submission about occupational health and safety and about how much even getting simple things done, like getting put in and out of bed or getting transported from point A to point B, can be made difficult, and to a large extent unnecessarily so, by the importation of official rules and regulations for what should be, in my view, personal, private arrangements and contracts.

MR WALSH: Thanks, Adam. Just exploring that a little bit. We heard in the previous submission that there's a notion of government responsibility to provide safety for citizens. Do you see any role in government in requiring that these personal arrangements that you seem to be espousing should be under any regime of quality and safety?

MR JOHNSTON: I am aware of quality and safety regimes, that there are any number of these in any number of industries. On the face of it, while I understand the intent, I think they have generated a lot of paper, a lot of frustration and a lot of cost which has actually meant either a rigidity of service or a reduction in service as resources are diverted to supporting the paper tiger that is health and safety. While I accept that some people will attach a level of security to an external health and safety office or regulator, the problem with any regulator is the moment you put in a regulator you've increased the cost. So that will probably have at least some effect of taking those on lower incomes, or who maybe don't have an income, out of the possibility of receiving some services or perhaps any services at all. So there's always a trade-off with safety.

If I was to speak just a bit more generally, governments are there for peace, order and good government, but in the modern welfare context it also appears to have changed into something about protection, care and good behaviour. I accept that there is a measure of government role there but I think, as I referred to earlier, there can be a level of prescription at the level of the individual which, to my way of thinking, verges on being undemocratic when you're virtually telling people what they can buy, what they can eat, where they can go, to service some broader public policy objective.

MS SCOTT: Adam, thank you very much for your submission to us and for appearing today.

MR JOHNSTON: Thank you.

MS SCOTT: I now call for Douglas Herd to come forward, please. Douglas, just before we start, I might just make a short announcement about lunch. On the original program we were going to go to lunch in about 10 minutes or so. We're a little bit behind in our schedule but very keen to hear from Douglas and to give him sufficient time. So with your forbearance we'll go to a later lunch. We might resume later and we might adjourn later in the day. I would like to give people their allocated time rather than squeeze people down in their timing. So, Douglas, could you please state your name and the organisation you're representing, please.

MR HERD (DC NSW): My name is Dougie Herd. I'm the executive officer of the Disability Council of New South Wales, which is the official advisory body on disability in this state, its members appointed by the cabinet to give advice on any matter of public policy with regard to its influence and effect upon people with disability. In the light of the last contribution, I should of course declare an interest in that I'm a public servant employed by government as part of what I understand to be the 21st century social contract between taxpayers, the elected parliament, its executive and the departments established to deliver social policy. I'll be as brief as I possibly can, which does not always mean "brief" with me, I have to be perfectly honestly and say.

I could, I guess, in speaking, cut my comments down to that thing that the Disability Discrimination Legal Centre said, "We agree with." I thought it was a well argued and represented view of what I suspect or believe would probably be a very, very dominant view within, say, non-government advocacy organisations in Australia about the current debate and how it might shape public policy in the future. Our council will give you a written submission, we haven't got it finished yet but we will by the deadline, and also beg your indulgence to allow me to say some things that might not end up in our final submission because my council say, "Jump," and I say, "How high?" and I haven't been told how high to jump by them in every detail yet.

I'm going to start at the same place as the DDLC, which is with the United Nations Convention. I'm sure you've heard it from lots of other people giving evidence and you'll hear it more. It's a paradigm-shifting instrument of law. In a hundred years' time when we look back on the history of people with disability we will see milestones along the way and the Convention will be one of them. There is before and after the Convention, and in Australia there is before and after its ratification. The act of ratification means that public servants like me have no choice; we are guided by its principles whether we like it or not. It's the settled will of the Australian parliament that Article 3, the general principles, will apply to public policy.

It's not a debate, it's not a matter of choice or personal preference or ideological inclination; it's a matter of the settled will of our democratic parliament that we should give, in Article 3, section 1, "Respect for the inherent dignity, individual autonomy including the freedom to make one's choices, and independence of person." That is non-negotiable and this discussion needs to be couched in those terms. I think there's a risk, a temptation, for many of the participants in this discussion, and I'll be guilty of it myself, that what we will do is we will debate how things have been in the last 20, 30 and 40 years, and that's interesting, you couldn't know where you're going to go, you need to know where you've come from, but that's not what this debate is about; it's about how the future will look.

I refer you of course to Article 19 of the Convention, living independently and being included in the community, which sets out the obligations of state parties in this particular realm of social policy and, again, its instruments are non-negotiable. So there's the Convention. We all know about that and there it is, we all have to just learn how to live with it and make it real in the future. Before saying some other things can I quote from another document. It's not part of the public policy framework yet so I can't tell you where it comes from, or if I did tell you I'd have to kill you.

MS SCOTT: You've got us intrigued.

MR HERD (DC NSW): Believe me, in a matter of weeks it will be one of the most commonly referenced documents in the disability sphere. It will be signed by those of the highest authority - used to be a man, now a woman - guess where we're coming from. So these are not my words but they're important. They say, "Our shared vision is for an inclusive Australian society that enables people with a disability to fulfil their potential as equal citizens." It goes on to say, "People with a disability must be afforded the same rights as all other Australians. Australia formally recognised this by ratifying the Convention in 2008 and by acceding to its protocol in 2009." They go on to say in the text that will become public very soon, "People with a disability are citizens with rights, not objects of charity." They then go on to say, "The experiences and needs of people with a disability and their families are central to the strategy, its vision and its principles."

I'm not going to argue with the list of signatories who will append their names to that document at the quarterly meeting of heads of government in the not too distant future. That therefore sets policy within the context of a legal instrument that is the Convention, giving us a clear indication of where our public policy needs to go in this area. I believe, we believe, I think this country believes, that there is a social contract between its citizens and its government. I think it's interesting and helpful for me and others to remember that the debate you're asking us to be party to goes to the very heart of what government is about in the modern society. It is therefore not about touchy-feely disability social welfare policy in many respects, it's about the relationship between people and government.

I'm unambiguously and unapologetically a believer that the social contract established in the 20th century was a good one. We pay taxes and out of those taxes we should get good public-funded services. For the vast majority of people now, in 10 years' time and in a hundred years' time, they will be absolutely dependent upon services funded by taxpayer contributions and that therefore we're talking about how we best organise those taxpayer-funded services. Without any disrespect to any other contributor to the discussion, it is fanciful nonsense to imagine that the three and a half million people with disability plus their families, dependent upon the massive industry that already exists to provide social services, can somehow go back to a 19th or 18th century fiction in which the family is the natural bearer of the burden of the accident, injury or illness that produces disability.

We haven't quite left the Dickensian model of social welfare for people with disability but we are moving away from it. Anyone that wants to suggest that we should go back to that future is, in my humble estimation, seriously ignoring the 20th century and everything we learnt from it. What do I think we should do? What do we think we should do? I'm British by birth, although Australian by choice. I was born and lived for the first 42 years of my life in the UK. I do not have a problem with social insurance models of welfare and care. I know we're supposed to be all patriotic about these things but it is, without any shadow of a doubt, the case that the finest health service in the world is the National Health Service of the United Kingdom; by leaps and bounds it's the head of every other health service on the planet.

It's funded out of a national insurance scheme. It's perfectly straightforward. Everybody makes a contribution. Employers make a contribution as well. Everybody understands what it's for and, when you need it, it's free at the point of delivery. Very simple model, but not without controversy and I think that's useful to remember in the course of this debate. In the recent election in the UK the sitting government proposed an increase to the national insurance contribution, it was the first of the policies attacked by the opposition in the general election campaign. I don't think any of us should underestimate the difficulty that any of us will have in trying to propose any kind of hypothecation of taxation into the future. One only needs to look at what happened around the rather bizarre discussion, in my humble opinion, about mining tax and taxation, to see how deeply controversial these questions can become.

I have a personal view - it doesn't really matter what that is, but I think it's incumbent upon us all, particularly those of us who want to propose, as many will do, that we have a Medicare-type level or an enhancement of the Medicare levy in some way, or some other form of hypothecation of taxes - that will be a deeply contested public policy when we get to the snippy heart of it. Unless I'm much mistaken, there are few successfully elected governments in the history of the OECD who have won elections by going to the electorate and promising to put up taxes, and that successful opposition, sometimes wishing to be opportunistic, let us imagine, often finds it easy to find the clear, blue water being it and the government when it says, "No new taxes."

Yet, the scheme that many of us favour here is absolutely dependent upon a reformation of this bit of the taxation system, and therefore those of us who believe that a national disability insurance scheme, or whatever it might be called, is a good thing, need to understand that we are going to have to fight tooth and nail to get that insurance scheme up and running. So my praise therefore to those who have led this campaign and have taken it to this stage. But the work has still got a long way to go. A fundamental, perhaps the fundamental pillar of any scheme, needs to be the empowerment of individuals with disability, full stop.

If we're going to add a bit to Medicare and we're going to collect it in a big pool and we're then going to disburse it to individuals, completely reshape the system by giving power to the end user. I like movies, they're where I get most of my inspiration from; the key line from All the President's Men is, "Follow the money," and in Jerry Maguire, the key scene in the bathroom is, "Show me the money." As flippant as that may sound, there's a fundamental truth there. The time has passed when the social welfare contract, in which I'm a strong believer, can simply fund organisations to do their best to provide services. Those non-government organisations have by and large done a very good job, they have done to the best of their ability what has been possible for them to do.

I have to say I'm tired of hearing people tell me that the system is broken. The system isn't broken at all, the system is just no longer appropriate to the circumstances. Forgive me, anyone who thinks I'm being unfair here, but if you pick up any annual report of any non-government organisation or any annual report of any government department you will not find the words anywhere inside them, "broken system," you will find, "We are doing a really good job," "We are doing this to the best of our abilities," "We're keeping our administration costs as low as possible," "We're trying to get as much as possible of our dollar directed to the end client as possible."

I think their task is impossible ultimately, because the real shift that needs to take place - it's not between government and non-government, not between provider and purchaser, but between the arrangements that we've had in the past and the end user. That doesn't mean that everybody gets a direct payment. I have some history here. I was involved in the establishment of the first direct payment projects in the United Kingdom in 1986, in Edinburgh, technically before they were legal, but that doesn't matter, we had an enabling local authority who was able to make that possible.

What is absolutely clear 25, 26 years later is that still in the UK most people don't want direct payments. They're too busy getting on with their lives to have direct payments. But some people do, and for those people who do, who can and will, that needs to be part of the spectrum. But we certainly needed personalised and individualised funding. I, as a public servant, need to know how much is being allocated to any individual who might be getting support through the scheme. I, as an end user, because I also am that, absolutely need to know how much has been allocated Dougie Herd's name so that I can then begin to ask informed, intelligent questions about how that money is being spent, I'd like to direct it in this way, that way or another way.

But for me to be able to begin to exercise those choices, I need to have that formal power in the process. How should it be organised? I'm not speaking here on behalf of the Lifetime Care and Support Advisory Council, which I chair. I do happen to chair that advisory council. I think the New South Wales model is not a bad one to look at, to understate the case. I think we should have a stand-alone organisation that gets the ring-fenced funds. I think we should have a bunch of people, like the board of the Lifetime Care and Support Authority, whose sole expertise is how to make loads of money, that they should invest it, they should use it to the best of their ability to get that pool to grow to be as big as it possibly can and that's all they should be interested in.

There should also be, as there is in the Lifetime Care and Support Authority, the touchy-feely side of the equation, which I chair, which is the policy-formulating advisory council, that says, "Thank you very much for getting all that money. Here are the parameters within which it should be spent. The policy is about what it will be spent upon, what can or can't be spent by the people making choices," and that, "Those policies get gazetted by parliament," and that, "That advisory council," whatever it should be, "should be comprised in the majority of people with disability, drawn from a combination of the public but also democratic, representative, accountable non-government organisations of people with disability," and that's some kind of hinterland from which they can come.

I think we should then let people go on and organise it. Individuals make choices. Professionals give them their advice. There's the development of new types of services, some of which will be service provision, some of which will be capacity-building, some of which will be advocacy, some of which will be information. We should do all that and review it every year, that's what I think and I hope.

MS SCOTT: Thank you. We might pause there and see if there's some questions.

MR WALSH: Thanks, Dougie. You've described a quantum shift in the way in which the social contract is delivered in Australia. Part of that social contract requires the community to have regard to the rights and inclusion of people with a disability.

MR HERD (DC NSW): Yes.

MR WALSH: Some people have told us in our hearings that that's not the case at the moment, and at first glance, given the amount of discrimination that still appears to be around, you'd have to agree with that. Do you have a view on how best to move in the implementation of a disability support scheme or insurance model? The success of that will be facilitated I think if there's a better cultural acknowledgment of the rights of people with disability. Do you have a view on how that might be achieved?

MR HERD (DC NSW): Slowly, sadly. I think we could do a variety of things. One is in formal, old-fashioned, traditional marketing strategies in which we're trying to say, "These people are not scary. These people are not second-class citizens. They're all right," you know, and we can do that very well. Here in New South Wales the Don't DIS My ABILITY campaign for instance does a very good job of it once a year raising the public profile of ordinary people with disability getting on with their lives. I think, to be honest, the long-term solution lies in resourcing individuals with disability to get on with their lives and to engage with a complexity and difficulty of life.

You know this as well as I do - and probably better, I suspect - that some of the attitudinal and other barriers people like me face have been eradicated, have been brought down and will be removed. Eventually, thanks to things like transport standards, we will, once upon a time, get to a day when there aren't any buses that aren't wheelchair accessible. So those kind of easy barriers are beginning to broken down. But they take a long time. Far more fundamental I think and much more difficult to engage with are a set of barriers of attitude, rather then physical environment, that relate to people particularly with a cognitive disability or some kind of mental ill-health.

Here in New South Wales we have got examples that are legion. A bunch of people in Goulburn got together and bought a house, rather than allow the department to buy it to turn into a group home. People writing into newspapers saying, "We don't want a group home in our community because there's a sexual threat if people with an intellectual disability come and live with us," "If anyone with schizophrenia lives in the town, somebody is bound to be stabbed the day after they move in." Those attitudinal barriers I think are going to remain for a while, and I think they're much more difficult to overcome than whether or not a building has got steps at the front door or not.

I believe that the only real long-term solution is to get - as scary as we may be - out and about, living our normal lives, going to work, the restaurant and the theatre, using whatever facilitating and enabling resources government can make available, through non-government organisations and other ways of supporting us, the companion card, the taxi transport subsidy scheme, the disability support pension, whatever these things may be, that get us out and about, so that folk will learn that we don't bite.

Sometimes some people do, it's true, but there are ways in which non-standard human beings can engage with the world that is, when all is said and done, pretty non-standard anyway. We all know it's a cliche, but there's no such thing as normal. Get used to it, is what I think. But the proof of the pudding is in the eating. Social inclusion happens by being included, not by talking about it. If I may - it's a long answer again, but forgive me - here's a thing I think that we also need to get used to, that people with a disability, some, and their families, some, need to get used to the idea that it's not a touchy-feely world, that there are risks, that bad things happen in the world, they happen to everybody, they happen throughout life, that we all hope we they don't happen to us, but sometimes they do.

That reality about life doesn't mean that we're negligent about putting vulnerable and frail people out there to have risk, but if there isn't risk in my life I'm not living, I know that for a fact, because the simple, ironic fact that is also true is that even in those places where we were supposed to be safe there is risk. But in the institutional living that we have created over the course of 200 years of social policy history in this country, risk for people with disabilities is everywhere. I'd just rather have the same risk as everybody else, to be perfectly honest.

If one is going down George Street trying to find a parking space one Sunday afternoon, Sydney might be hit by a meteorite. Chances are it won't. But if it's going to be hit by a meteorite, then people with disability will get smashed in too. I make it sound more simple than it is, but in the final analysis I don't think it's too complicated. Just do it, is what I think.

MS SCOTT: Not for now, but I certainly would welcome your views in writing about the role that services currently operated by the different states would play in the scheme, as you envisage it. I took on board your points about you don't consider the schemes are broken, no longer necessarily appropriate. But I'd like to know what, if any, roles they should play into the future. I am just conscious of time. So I think I'll take that in writing, if you don't mind.

MR HERD (DC NSW): Of course.

MS SCOTT: Thank you very much for your contribution.

MR HERD (DC NSW): My pleasure.

MS SCOTT: Now we are going to break for lunch.

(Luncheon adjournment)

MS SCOTT: Good afternoon. Welcome back to our hearings. I now invite the joint presentation from a number of organisations to come forward. I apologise for the delay, it was unexpected. So please join us now. Welcome. For the record, could you state your name and the organisations you represent. We had agreed that you'd have an hour and 10 minutes, so if you still wish to have that length of time, please proceed. We'll just go longer in the day.

MR JACK (MDF): David Jack from Muscular Dystrophy Foundation.

MS STRUGNELL (BSL): Sharon Strugnell from BrainLink Services in Melbourne.

MS BIRKS (MNDA): Carol Birks from Motor Neurone Disease Australia.

MS MORKHAM (YPINH): Bronwyn Morkham from the Young People in Nursing Homes Alliance.

MS SCOTT: Would you like to make a presentation, either individually or collectively?

MS MORKHAM (YPINH): I think what we'd like to do is just give a short introductory statement about our organisations and where we sit within this. Is that okay with everybody? I'll start. The Young People in Nursing Homes Alliance exists to resolve the issue of young people in nursing homes, obviously, and we're very excited to see this inquiry under way. It's something we've been agitating for for many years and particularly to have the Productivity Commission involved in this way. So we're very, very excited and very pleased to have the opportunity to talk today.

I don't want to take a lot of time. I'm very keen to actually have a discussion with the commissioners rather than present on anything and I sent up a rather convoluted set of notes that you probably got to have a look at. I really just want to say that we are very much keen to see systemic reform of the disability service system. We do support a social insurance levy as a funding base, though we do have some ideas about how that might work in practice. So I'll just stop there and say I'm really looking forward to speaking with you. Thank you.

MS BIRKS (MNDA): Well, Motor Neurone Disease Australia represents the six MND associations who provide services and support to - there are approximately 1400 people living with motor neurone disease at any given time, their carers and family and friends. MND is a rapidly progressive neurological disease with a spiralling series of losses related to communication, mobility, speech, swallowing and also breathing eventually. So average life expectancy is only around two years.

We really welcome this inquiry. Access to service is vital for people with motor neurone disease. It needs to be a rapid response to service, a rapid response to unmet need, and we hope that this whole of government approach in this inquiry will look at unmet need as a priority.

We feel that this is a unique opportunity and we look forward to providing you with a detailed submission on our needs. We, too, believe that this needs to be an entitlement scheme; it needs to be funded through a Medicare-type levy; and it needs to be for all disability and diseases, whether they're acquired at birth or throughout your life. So I'll just leave it at that and maybe when we finish I've got some dot points on what Motor Neurone Disease Australia and people with progressive neurological disease need and I'll refer to that later.

MS STRUGNELL (BSL):   Sharon Strugnell from BrainLink and I will just make a couple of points and then I think the interaction is probably more important. We're a Victorian organisation and we are a support organisation for people with acquired brain injury and also neurological conditions. We provide education and support services, information and referral, respite services and we also have been, since its inception, part of the Slow to Recover case management slow stream rehab program in Victoria, and we provide significant carer and family support to the community. A couple of things I want to bring today.

Just thinking back to Dougie's presentation just before lunch, which inspired me no end listening to him, being a Victorian, I have to say that as a user and a public person I'm used to paying my tax to have TAC cover, so I know that if I'm injured in a car accident or a traffic accident that I'm covered. I'm used to paying my WorkCover levy because I know that if I'm injured at work I'm going to be covered. I also know, because of my work and the work that I do, that if I'm injured in any other way or I acquire a condition or a stroke or some other form of neurological condition, that my coverage isn't that easy and I'm at the hands of the public system.

I do have to say, though, that in Victoria we are fortunate that we have a small program, which is the Slow to Recover case management slow stream rehab program, for people with profound and severe brain injury. BrainLink itself, it's a brokerage program and we look after 36 clients currently on that program. It's not the perfect program. It has faults, like any scheme, but there are some really good things about that program. Obviously in our submission we will share some of those things. Thinking back to something someone said earlier this morning, I think that whatever the service delivery model is, it needs to look at some of those schemes in New South Wales and Victoria that are running already and, at a bare minimum, take the best of those schemes and then look at where the gaps lie, and I'm sure that you're looking at that kind of thing.

Just to say a couple of things about the Slow to Recover program. It has evolved since 1997. When it started, one of the difficulties with it - it's a very expensive program - was that throughput was very slow. It is very much for severe and profound people and getting them off the program became a bottleneck and it's still a very difficult thing. However, in recent times I can say with our own clients, just this year and late last year we have three clients that have moved off the program and have taken up generic packages. So that's a really exciting thing. Two of those clients have been on the program for 10 years, so that was very, very exciting. The other thing that has just recently happened in the last six months, we actually have two clients who are part of a pilot program because they wish to manage their own funds.

So we are part of that pilot with the two families and individuals with brain injury to manage those funds. I will say in the first onset that one is working very, very successfully; the other we are having issues and we're having issues around professional staff that are now being changed and occ-health and safety issues, a range of issues. They're just some of the things to consider. Within a system we applaud what's happening and I think that it needs to be on individual need and it needs to be an assessment that is done frequently and that staff or the people that are involved certainly in the assessment really have an understanding of specialised illnesses or conditions. For instance, something like ABI, the cognitive issues that present and behavioural issues, we really need to know that people are going to understand those issues within their assessment. There are plenty of learnings. I'll stop now and hand over to David.

MR JACK (MDF):   David Jack, Muscular Dystrophy. Muscular dystrophy is neuromuscular, it's genetic and it manifests in a number of different ways. Certainly a child typically with Duchenne muscular dystrophy, which is the most common form of muscular dystrophy, is diagnosed average age three years 10 months. By age seven, eight, they do require wheelchair support. By their mid teens they'll need ventilation and typically will not survive beyond their late teens, 20s. There are some notable examples of young men who are now 30 with Duchenne muscular dystrophy. So you can appreciate that there is an immediate and a devastating effect on a family and, given the progressive nature and given the circumstance, it involves a very significant change and a whole range of very significant issues. There is a mature age onset form of muscular dystrophy as well. So it can affect people right across the community.

The Muscular Dystrophy Foundation represents and supports state associations. We have roles around research, awareness education and fundraising, and the state associations typically provide services. Although the title would appear that we support people only with muscular dystrophy, in fact we support people with neuromuscular conditions, of which there's 80 to 100. The muscular dystrophies sit inside that; there's eight or 10 of those. So we have quite a broad spectrum of clients that we support. In all, about one in a thousand Australians are affected, so about 20,000 Australians have the potential to acquire a neuromuscular condition and be supported by an organisation. I guess, as the others have said, we are delighted that there is this opportunity through the Productivity Commission to speak to the broad range of issues, and there are many, and some of those will come up as we have a conversation together.

Just three or four very broad statements. Firstly, we do need to approach this from a quality of life perspective. This is not just about providing the basic essentials, it's not just about equipment, a wheelchair, it's not just about a home modification, it is about quality of life. I think it is also about whole of family. It's not just about the person with the disability. We would estimate that for every person with a disability there two to three people immediately affected who live in the family home and then there's extended family, friends and so forth. If you look at it through the eyes of the person with the disability, if they're to have a true quality of life, they need the opportunity to develop relationships beyond the carer and to have access to the community beyond the four walls of the home in which they live. So it is a whole of family issue.

It's also a whole of community issue and it's very disappointing when we speak with families who have multiple regimes to deal with, multiple systems to deal with to access the basics of life and sometimes they're whole of life is consumed by these multiple systems and regimes and the frustration that goes with that ultimately leaves families to throw their hands up in the air. So we just need to acknowledge it's whole of community as well. Finally, whilst there might be some very good ideas around how we deal with some of these things, that ultimately it is the choice and the decision-making role of the person with the disability that needs to be respected and honoured through this process. So perhaps there's just a few comments to kick us off and we perhaps can have a conversation together.

MS SCOTT: I might start, if that's all right. I'm interested in discussing assessment methodologies with you, something that you're probably each expert in or have some exposure to. So, firstly, simple-minded economists, take it gently. Someone yesterday giving testimony pointed out the ACAT model and how successful they thought that was in terms of assessing people for aged care and so on. We've been looking at a number of assessment tools and have reached no decision on it. We know that there's a lot of different assessment tools out there and that a number may be particularly suited to particular conditions and so on. What model would you advocate to us, what reading do you think we should be doing - you can take that on board as homework, if you like - but I'm interested given the range of conditions and the range of interest groups that you represent, if we're going to have a national scheme and we're going to have national standards and we'd like to think that you would get an equitable outcome regardless of where you live or who the assessor is. How do we have something that could be widely applicable and credible to each of the different groups that you represent?

MS MORKHAM (YPINH): Can I start off, at the risk of leaping in. From our point of view and young people in nursing homes are largely those with acquired disabilities and very high and very complex clinical and other support needs too. So I'm coming at it from a bit of a mix of health and I think all of us have from our own organisations have young people who end up in nursing homes because the system can't respond adequately as it is currently situated. We believe that the way to look at assessment is really from a risk management perspective, not going to a particular tool to do this. I'm not convinced that the assessment tools out there that are currently used are all that great. I think many of them come from the medical-model type which we need, I'm certainly not discounting that. But as David has said, families are involved, there's a social person that has to be addressed as well.

Ultimately, we see this as a process of defining risks in the short, medium and long-term and putting in place a series of responses that address those risks as they come down the pipeline. The planning for this is paramount. We were tossing this around at one point and I thought the enormity of what this scheme is going to have to do is large and if there's one thing that it would pay to do from the very outset and take time to do is to get the planning process right without going into what do people get, what services might they buy with the money that the scheme might have. If we can't get the planning process right, the rest of it will fall over. The planning process is also important because it will reveal the service gaps. We know what many of them are, others are much more subtle. So I think getting that planning right, using a proactive risk management approach to define what are the risks for that person.

If I can just give an example here from the Younger People n Residential Aged Cared initiative which has been ongoing now for nearly four and a half years has, despite its evident flaws, delivered a quantum of information that is of use in determining these things. We were part of a group that put together a trial project in Victoria, MS and BrainLink were part of this as well, to look at how we could provide a continuum of care to young people at risk of placement in nursing homes, in that it was a proactive risk management strategy that we took and it went to things like - we had one gentlemen whose biggest issue at that time was how to stay in employment, paid work, how would he negotiate with his employer - and I guess this is part of what I'm heading to. It isn't just around physical needs as such or the other cognitive needs that we may identify.

The scheme then addressed that, the scheme went and worked with him to go to his employer, to put in place the structures that he needed to have certainty about his time going forward. It identified the risks for the employer and for him and did something about it. We had another young woman who was in the end stages of a terminal neurological disease and her biggest worry was what would happen to her young children; she was a young mother. The biggest risk for her was that she would pass away and they would end up in the social welfare system. So what we did at that point was to look at identifying with her - support her to identify who the guardians she wanted for those children were, approach them, get a solicitor involved to draw up a will. We also put in place some other services that she required.

MS SCOTT: Bronwyn, I might get you to pause there because I think I'm on the wavelength but I just want to check. That's about assessment of what the person now needs, I've got that. I think I've got that right. So for one individual it can be completely different to another, employment versus future care arrangements. But I'm also interested in assessment into the scheme.

MS MORKHAM (YPINH):   Eligibility.

MS SCOTT: Eligibility. You're looking at assessment and need once they're in the scheme. But we've got a diverse group of people in front of us now and is it likely that we could find something that all of you would think - you know, it could be multi-allied staff that would form a team like ACAT that would assess and if we used a particular tool all of you would say, "Yes, that's about right, but your professional needs to have some flexibility in that." You might have a view but I'm actually talking about assessment in terms of determining eligibility and then after that it could be about what individual need is. But I just want to talk about the gatekeeping assessment, I think.

MR JACK (MDF):   I think there are a number of elements to it. I'm sure there are tools that could deal with physical disabilities that could be stretched across many, many; there are tools that could deal with cognitive and intellectual disabilities which could be stretched across as well. I think one of the challenges is the changing nature of the condition where it's progressive and the challenge there is whilst we may be able to get an assessment to bring a person into a program or to be considered eligible, there are multiple and numerous milestones during the life of that individual where they need continuing assessment process to ensure that their ongoing and changing needs are acknowledged, understood and met. So for some to have their three-year-old assessed as being eligible for some kind of support is the first in a series of - - -

MS SCOTT: Yes.

MR JACK (MDF):   I think partly it's about an assessment process that's ongoing whereby you don't have to keep - there's some anticipation of need and so on.

MS SCOTT: I think we're okay on that. We've got a couple of models which are about you don't want to keep going back to people and saying, "Do you still have that congenital condition? Have you still got it two weeks later?" But other people are going to be degenerating - - -

MR JACK (MDF): It's degenerative as well.

MS SCOTT: Right. So we've got that.

MR JACK (MDF): Yes.

MR WALSH: What this does say is that measuring just at a point in time is probably not going to do it for everyone, so one of the other things that needs to be in the assessment is some sort of a diagnostic of what the actual condition is and what the prognosis is over a review period, if you like.

MS BIRKS (MNDA): Can I just jump in there as well. You were referring to the ACAT model and I think it's important with any assessment process that there needs to be somebody that understand the disease, understands the disability, so has an idea of how the progression will be so that they can make that assessment with that in mind in that first instance.

MS SCOTT: Can I just check on that because if it's a national scheme and we're servicing the people in Deniliquin and Albany and Fitzroy Falls and Fitzroy Crossing, we might not necessarily have specialists in every disease and so on and some people are cautioning us, "Don't follow a medical model," and other people are saying, "It's about the social as well as the attendant care." Could you talk about how you think this could be operationalised - I mean, there are things like planes, you could fly people in but they are expensive and there are telephones and there's broadband. Could you talk about - because in one way one of the things we will have, I think, as we write the report, is we need to come up with a credible and affordable and sustainable scheme and if the first thing that happens when we finish our draft report is that each of your groups comes out and says, "That's not good enough, they do not have enough familiarity with the type of conditions that we're most concerned about," then we will almost fall at the first hurdle.

So I'd like you to think about how we could truly operationalise your reasonable expectations and if you could think about those different settings. Now, it might work well for Brisbane or Melbourne, but what's going to happen in Fitzroy Falls and Fitzroy Crossing and Deniliquin? Could you try that?

MS STRUGNELL (BSL): Could I say that I think that's a very difficult task for you to have experts in everything wherever, but I think what is overarching to whatever system comes into place is information from the onset and it's about information about a system but it's also to all sorts of stakeholders, to the person with the disability and their families but to all the professionals involved, the government, the bodies, whoever it might be. Now, I understand that you're not going to physically have somebody with motor neurone experience, someone with ABI experience, whatever but there is a range of materials that whatever bodies are developed can come up to speed at the basic minimum of understanding. In the first instance the things that are needed for a physical disability as compared to someone with cognitive issues and then very specific, and whether it's a range of materials, whether it's a range of referrals to the peak bodies and the right people, but it gets that to whoever are on these assessment bodies or whatever, they need to be open enough to be able to see what somebody needs and to ask for more information if they need it.

I think the information is easy to get. It's not difficult getting information but it's about, getting back to something David said, certainly with our slow to recover clients part of our assessment - I mean, it's very easy, "Do they have an ABI or don't they? Is it a diagnosed ABI?" If they are, they come into the program depending on rehab. But once they're in, what we do is we sit and we listen to the person if they're able to communicate and their families and that's where the information about their needs comes from. But I think whoever is there can gain information and learn information and training, whatever it might be. It might be fact sheets on motor neurone and fact sheets on the bare minimum of the most important things that need to be considered, I believe.

MS SCOTT: Okay.

MR WALSH: This question might lead into - Bronwyn, you've got some suggestions on funding and so on. We've been talking about assessment, we've had a number of testimonies that advocate things like the In Control model in the UK which is self-assessment. Have you got any comment on that?

MS MORKHAM (YPINH): I think for many of our people that's a difficulty. I don't know that sometimes people can make a self-assessment and I'm not all that convinced. If you've got clinical needs, as our groups do, you need clinical expertise to deliver that. I was going to raise the notion of member organisations and I think we already have in place a mechanism that you could use. If you take these organisations here, each one of them has links back into clinical services, they'll know people that can be called on.

I want to raise the idea that from a variety of points of view that member organisations ought to be at the heart of this system of assessment, planning and brokerage of service delivery as well. They already have the connections there. If we're talking about what assessment tool, that's a whole other area that I'm not an expert in at all. There's a range of them out there. The ACAS model was developed specifically to determine level of need for aged people. I don't think it's at all applicable for us. But it's also dependent on a very regressive notion of limited funding availability, so it's not a proactive model at all, I don't think, so I'm meaning from that point of view, Patricia.

But if we take member organisations and what they already do, then I think there lies a potential solution to this and I think we need to involve the medical profession better. In what I've said I was articulating a team approach but I didn't mean a precise team that lived as a team all the time, you'd bring in people as required. If you have somebody with ABI, you'll go for a neuropsych assessment maybe with a neurologist or whoever. If you have spinal cord injuries, it will be a whole different kettle of fish. But the member organisations hold that information and I think - many of them already do this to some degree or other. I know the MS Society in Victoria does, it has clinical specialists on site that go out and work with their clients. I wonder whether that's part of the answer here, to go back to what we've already got in place.

MS BIRKS (MNDA):   I think also we've got some models out there as well with motor neurone disease and case management type services whereby there's a partnership approach and the person is monitored by the MND Association regional advisers as they progress and alert the service providers when needs are changing so that they know they need to step in or step out or whatever. So there are those models already in place that we could draw on and build upon, I think.

MR JACK (MDF):   Just to touch on the self-assessment, I think there is a principle there that we do listen to what people are saying. A parent can phone and give us enough information for us to be acutely aware of what their current need is without going to see the child. They know what they need, "We need a wheelchair." But I think there's a problem around funding and it's very easy to delay support and question assessment based on a distinct lack of funding. We've got two boys in two different families right now who have been waiting two to three years for a home modification so that they can shower. Disappointing, devastating, frustrating, you know, there's anger, all kinds of emotions for that family because that child is not living a normal life, enjoying the very basic things that we all enjoy.

The assessment is clear. I think in many respects, whether it's a parent who can make an assessment or an OT or a neurologist of, indeed, a case worker who's part of a patient support group. I don't think the issue is around, "Can we make an assessment in a timely fashion?" It's very much around, "Can we respond to that assessment in a timely fashion."

MS SCOTT: I'm sure you're right but the reason why I'm asking is because in the DIG report it referred to, I think, John, the German scheme that started and gatekeeping entry ended up becoming an issue in terms of its sustainability. In some ways because we're all very conscious of high-end needs and so on, but we've also heard that sometimes it only requires an hour of assistance and someone can live independently, we could now be looking at a very large group of people and the report that John and others worked on had different population groups.

But we're dealing with substantial numbers, David, and I guess if it turns out that there are then issues about entry into the scheme, it actually could affect the sustainability of the whole scheme if gatekeeping isn't effective. It's got to be fair, it also has to be effective.

MR JACK (MDF): Yes.

MS SCOTT: I take your point, someone having to wait three years to get a shower for someone that has a severe impairment seems clearly dysfunctional. That's not right. I'm sure an effective group of people could work with an individual to identify their needs. But it's actually the gatekeeping role that we probably can't dismiss out of hand because some schemes have had trouble with that.

MR JACK (MDF): I agree and you referred earlier to a sustainable system. I think it's fair to say that many of our families and clients, and maybe it's true for all of us, have multiple case managers and they're crossing over one another and they're duplicating effort and duplicating service. So if we could agree on the lead agency for all groups, if we could establish local area coordination so there was a lead agency that was able then to access on behalf of and with clients the services they require, instead of this duplication of the infrastructure around assessment, the infrastructure around advocacy et cetera and case management and so forth. I think there are opportunities to streamline and create a better system which will actually remove frustration as well as saving some dollars and putting more of the money into delivering the actual service.

MR KALISCH: Can I just ask one question on this assessment dimension again. A number of you talked about the clinical input to assessment and I can understand that in the client populations that you deal with quite regularly. I suppose one of the issues that we've see in another part of social policy in the disability support pension is, I suppose, some questions about the objectivity of that clinical advice, particularly where there's a patient-doctor relationship. Is there or can you think of a way in which we can have that clinical input, but have it as a more objective arrangement?

MS MORKHAM (YPINH): From our point of view, and just picking up on something David said about the multiplicity of case management, we actually believe a case coordination approach is a better way of going where you have somebody with authority - and I guess what I'm about to say goes back to the fact that this new system should be an adjunct to the existing disability system and the existing disability system has to continue to do what it does. It has to be continued to be funded for that and we need to improve funding there as well. But if we're looking at case coordination, we don't have anybody yet with the authority to go to the various arms of the service system, to health, to disability, to aged care, to housing and make them deliver what they should be delivering.

So one of the answers around what you're asking, David, I think is case coordination. How you get that clinical independence of assessment, I think again if you go back to member organisations who already have those links back into the clinical community, to the acute system, they will know where the people are who going to be able to deliver this. Again, in the pilot we did in Victoria we partnered with Bethlehem Hospital who is a subacute service for people with progressive neurological disease. Again, they brought in their experts as required and it was done from a very holistic approach that looked at the person, the families were brought in to contribute, everybody who had something to offer in terms of assessment came and put it on the table, so a very holistic response was developed. I think I've forgotten your question, I'm sorry.

MR KALISCH: It was just around the objectivity, getting the objectivity and clinical advice. But I suppose I'm still wondering from the other groups as well whether there's some experience that you've had.

MS BIRKS (MNDA):   With the MND associations their regional advisers already have that role in identifying and referring people onto the relevant services to meet that need - if the service is available - but the referral happens. So they have that monitoring role already and they help people to then navigate the system and try and identify key workers as well, whether it is that MND Association regional adviser or a case manager or whoever. I think identifying that key worker is really important. So that model is already there, I guess, and that could link into some kind of assessment process as well and work with the association to make that assessment.

Maybe this is also an opportunity for some diseases, like motor neurone disease, like muscular dystrophy to have automatic eligibility and to bypass assessment in some way but to have that ongoing review process so that services are there to meet the need.

MR KALISCH: Obviously one of the challenges with some of the diseases is that you know it's progressive, that you know there will be a change but you're not quite sure when and how quickly, how severely. So it's making sure - - -

MS BIRKS (MNDA): So it's having that person monitoring in the background is helpful.

MR WALSH: I think that's an interesting notion having automatic entry if you've got a particular disease. It's the way the lifetime care authority in New South Wales works with spinal cord injury, for example. Just thinking about that, are your organisations, plus spinal cord injury, I suppose, do you pretty much cover the neurological diseases? Are there any others that - - -

MS MORKHAM (YPINH): There are some, there's Huntington's disease.

MR JACK (MDF): Parkinson's, Alzheimer's.

MS MORKHAM (YPINH): Stroke association.

MR WALSH: How many of those are mostly late onset?

MR JACK (MDF): Well, Parkinson's, Alzheimer's.

MS MORKHAM (YPINH): MS.

MS BIRKS (MNDA): But all having a younger onset component as well.

MR WALSH: All have occasional younger onset.

MS MORKHAM (YPINH): Yes.

MR JACK (MDF): Whereas ours is the other way around, primarily younger but there is an adult onset.

MS STRUGNELL (BSL): ABI is anything, you know, anything, any time.

MS MORKHAM (YPINH): But if we're looking at the severe and profound end of things - I mean, our position from the alliance's point of view is it should be eligibility at diagnosis, but that doesn't mean entitlement and the scheme can't be seen as the lifebuoy, the golden goose for everything. So if you have an eligibility to the scheme, it should activate when you reach severe and profound and it should probably be after all the other arms of the service system have exhausted their contribution. So, for example, we know with rehabilitation for ABI - - -

MS STRUGNELL (BSL): We've got people leaving the scheme now, so it can go both ways. It can go up or down.

MS MORKHAM (YPINH): But if you're leaving acute care, at the moment the hospitals can provide a very, very limited quantum of rehabilitation. It isn't enough. Your example, Sharon, of people who were 10 years in the scheme but have eventually left. So if we take that as an example - if hospitals could provide, say, six months of intensive rehab for ABI and that isn't available anywhere else in a funded capacity, the scheme might then step in to continue that process or habilitation services for somebody with MS who needs to maintain life skills at a certain level where the health system or the disability system can't continue to deliver at the level they now need, the scheme might step in at that point.

MS SCOTT: Can I just explore a bit further - we haven't formed a view on this, so please don't take any sort of teasing out of the proposal as indicative of final decision. I can understand what you're saying when you say that if it's a lifebuoy to everyone, if it's a scheme for everyone then all resources, even increased resources are finite and that might mean that a smaller amount is available for those with severe or profound. But you would have hear evidence, Bronwyn, even in the course last day or two, some people saying that all they need is help out of bed in the morning and if we went with functional impairment, a person that just needs an hour might be at the bottom of the pile and people who need 24 hours, including ventilation, would be at the top of the hill. The services would vary, but the person only needing the hour would still be in the scheme.

Now, some of those people, it's apparent, that the services aren't always in existence in each of the states, so I'm interested in hearing a little bit more about the difference between you're eligible but you're not entitled because it's not sufficiently severe versus people who say to us, "Look, we only want an hour. Give us an hour and we won't go for the intensive 24-hour, seven days a week, but that's all we need." I'd like you to talk about that and just explore that a bit more, spend a bit of time on that.

MS MORKHAM (YPINH): If I can just say, this is the Pandora's box, isn't it, really because we don't have a disability system that can do that. Part of our concern is that whenever we - I do think we will get to this point, I am optimistic, and I hope we do get some sort of social insurance basis for the funding. But whenever that comes down we have an enormous and very immediate need to actually start developing the infrastructure now. We can't afford to wait until that comes into place. So governments have a role here and, again, I don't know how the commission goes back to governments to tell them what to do. But that example, Patricia, of one person needing one hour, that ought to be available in a very easy way of being delivered, yet it isn't for a whole range of reasons around pricing, funding, unmet demand and so forth; it isn't available at the moment.

To put it into place ought to be relatively simple, but governments have never had to do that. They've never had to try to get their heads around that. I don't know what the answer but I guess it comes back to demanding that the existing service systems actually do their job before. That example of eligibility, it should be after the other ones have exhausted their potential perhaps. Again, I'm not welded onto this as an idea, I'm just wanting to explore this. But maybe that's where you go back to Disability and you say, "This person only needs one hour. We're not going to provide it, that's your job. What we could do though is, say, they need a $30,000 wheelchair that nobody has capacity to provide, we can step in here and help you out." So I think there's got to be greater collaboration between those various arms, there's got to be flexibility.

I guess the other thing to say is that I think people with disability - and I'm sure you've heard ad infinitum - we are inured to complaining because there has never ever been enough. But I do believe that once people do see possibility they're not going to want to gorge, I think they will be very reasonable in understanding what is possible. They're not going to want absolutely everything. Certainly for my group, our group, who are largely people with acquired disabilities and have very different expectations, they're not out there to get everything. The just want a reasonable quality of life. I guess that goes back - if you look at the TAC in Victoria and, again, if I can just put this in, the scheme has to be a legislated authority somewhere and it has to hold the money itself, it cannot be allowed to go anywhere else but for that scheme.

If you look at the way the TAC does it, their test is around reasonableness. Somebody might need sea air and they might want to live in a penthouse overlooking the ocean. "Sorry, no, we can deliver this here, but you won't get the penthouse, you will get a decent place to live near the sea" - it's a silly example but you know what I mean. I don't know what the others think.

MS STRUGNELL (BSL):   I guess the difficulty is the mechanism. If I look at the TAC as an example as well, interestingly enough if you have an accident or a traffic accident of any kind in Victoria and you go to Emergency, it doesn't matter how minor or major, there is a mechanism immediately - you're handed a form, tick the box if this is WorkCover or if it's TAC and from there a process takes place. I had a personal experience in that my son had an accident, got a bit of whiplash et cetera, very minor, didn't need much but went through that process and so was seen immediately through that process, didn't really need anything apart from a quick check over, "We'll monitor you for a few days," and that was it, "See you later." However, he was in that system, the mechanism had happened and if he needed anything further it would have kicked in.

I think the system needs to be a social insurance system very different to TAC and whether again, you know, as a Victorian I'd want to see that we have the minimum of all those systems kept because that's what we've had. But it's much more difficult if you're - we deal with acquired brain disorders, if you're diagnosed with MND or diagnosed with Parkinson's or whatever, when is going to be your time? My husband has Parkinson's, has had it for 15 years but up until now doesn't need anything at this point in time, but may do in the next 10 years. So this is the difficulty I know and we've thrashed it around trying to come up - how do you enter, but not be entitled, but you just sit there for a while until you are entitled?

MS MORKHAM (YPINH):   It comes down to management of expectation I think too and, unfortunately, I think because people are so desperate for an answer there is massive expectation, "This is going to deliver everything for everybody," and it simply can't. I don't quite know how this is going to happen, whatever the scheme is, it will have a big job to do of education and awareness raising. Already I think there's going to be significant disappointment whatever is the answer that comes out from the commission. But I do think there's got to be a sense of management of that expectation from this point forward. All of us have a responsibility to do that somewhere, I think.

MS STRUGNELL (BSL):   And do we keep generic disability as it is and we have specialised disability running alongside it? I guess they're the things as a minimum.

MR WALSH: Could I just explore that a bit and go back to square one. You said a few times things like, "If the existing system does its job, this wont be like TAC," and stuff like that. Could you just talk about what you see this system as looking like. Is it something additional to TAC and the existing disability system or does it replace either or both of those things and expand it?

MS STRUGNELL (BSL):   In a perfect world a system that encompasses all of those things and it's very difficult to state because I suppose where you do come from a state where you have a certain system already for certain things you certainly don't want a new system to - - -

MS MORKHAM (YPINH):   You can't dumb down.

MS STRUGNELL (BSL):   - - - have anything less than that.

MS MORKHAM (YPINH):   Can I leap in there, Sharon, and just interrupt and say I don't think it should replace them at all. I think they have to be sustained and have to grow. I've even got a question around whether we still need something like a catastrophic injuries scheme because I'm very aware that this scheme cannot take in everything and I do think it has to start small in the first instance, be very small. I mean, the Lifetime Care Authority in New South Wales did just that, it started off with just children and then as the capacity grew it took in adults and now it's moving perhaps to something else. So whatever the time line is we're looking at and I mentioned before, get the planning right first. Even if we did that for the first two or three years and then moved up.

In another 10, 15, 20 years we may be at a point where we do need to rethink whether the scheme is a stand-alone, whether it does merge or meld in with these other things or whether it continues on as it is. But I think for right now it's going to be a big enough job to get this up without trying to roll everything in and all of those schemes have different legislative requirements, they've got different mechanisms, they've got different responses to particular injuries even that would be very difficult to harmonise, I think. So I think they've got to remain separate, for the time being at least.

MR KALISCH: Can I just take this a little bit further, I'm interested in this, like John and Patricia probably as well. We're hearing from a number of people their perspective that the system is just so broken that it needs a radical change, that more incremental change, building on what's already there, they see as quite inadequate. There might be a slightly different view in terms of the TAC, the long-term care and some of the workers comp arrangements that have a no-fault basis and provide lifetime services. But for the rest of the disability sector it's certainly the view that we've heard in many other hearings is we need to basically replace everything else that's there.

MR JACK (MDF):   It's always going to be tempting to want to do that because when you start from the ground up, according to today's needs, you would optimistically believe you could do something so much better. The reality is that the people that we deal with just don't need access to healthcare, they need access to education, they need access to employment services. They need to be able to go down to the local park and know that someone has put some thought into how it's been designed. They need to be able to go down to the local shopping centre and know that they can get into that place and go shopping and enjoy the experience and go and see a movie and go and watch an AFL.

What do we do? Do we reinvent the whole of Australia or do we step back and say, okay, what we have to do is provide a mechanism that firstly resources the parts of society that our clients and patients that need to access better resources in them, so that when they knock on the door someone doesn't say, "Come back and see us in two years." Somebody says, "If you need your home modified, if you need a piece of equipment, if you need, if you need, we can provide it in a timely fashion according to need." So I think that's the first thing, resource the existing systems. A lot of the complaint is not about the system. The systems have typically been fairly well designed and thought through by smart, competent people. They're not resourced adequately.

I think the second thing is provide a mechanism for access. Give people a card that says, "I have a legitimate requirement around a whole range of services," and if the card then says, "I'm a category 1, 2, 3, 4, 5, 6, 7," which means "I can go here, there," so on and et cetera, give people a much greater capacity to access the services and I think, secondly, step them through it, guide them through it. A lot of people don't know what's going to happen tomorrow in their life because nobody has sat down and said, "Look, you've got a three-year-old but in about two to three years you'll need a wheelchair for that child and in about five to six years you'll need a ventilator and all of that is going to be really scary."

So we need mentoring. That's where patient support groups are so valuable because they connect people with disability and families with other people with disability and families, so you get a mentoring that occurs. That's sometimes just as important or more important than the health professional who is vital, but the health professional is not always going to be concerned for the ongoing social, physical and other requirements around life.

MS BIRKS (MNDA): I think what we haven't talked about is the individualised funding as well to empower people to enable them to purchase services or someone to act on their behalf to purchase services to meet their needs. That will then drive better service provision in our community. There are some great models out there, some great services but they need to be resourced and they need to be supported.

MS SCOTT: Thank you. I'm conscious we're just coming up to the end of your time and for the people that have just joined us, unfortunately, we're well behind on our schedule, so if that's going to cause any problems, please talk to Hudan as soon as you can and we'll see what we can do. It's been very instructive for all of us today to hear from you because your perspective is quite different from some of the other things that we've heard. I'd have to say on individualised funding we tend to hear the same thing and in some ways that's sort of coalescing in our minds.

But in relation to this scheme that you're envisaging, it's quite different from others and I would certainly implore you to think about documenting it and you have particular insights to things that would be worth us reflecting on. For example, the role of mentoring, first contact with the person, we have been thinking about that but your perspectives would be very useful. If I had advice for any group, including those reading the transcript, it would be that they may think about principles, which of course is very good, and frameworks, which is very good, but at the end of the day this needs to somehow be operationalised, it needs to be introduced, it needs to be feasible, it needs to be sustainable, so thinking about if you put the person and their family at the centre, what's the first step and the second.

I think, David, you were giving us some good advice about how that might actually be, the role of mentoring and the role each organisations and in terms of me worrying about Fitzroy Falls of course, if somebody is end at the of the line and can tap into a specialist, then I don't need to be so worried about that. Thank you very much.

MR WALSH: Just one thing that you might include in your submission and that is your groups, I think, are - more than most that we've heard of - linked to medical support. A lot of people we speak to are stable disability, all they want is personal care, keep the doctors out of it. So that transition or, if you like, the collaboration between the health system and the disability system would be useful.

MS SCOTT: Thank you very much.

MS MORKHAM (YPINH):   Thank you for the opportunity, it's been terrific and we'd really like to keep this dialogue ongoing.

MS SCOTT: Bronwyn, I think you're coming back for the next one, aren't you?

MS MORKHAM (YPINH): Am I? I thought that was it. Am I on now again?

MS SCOTT: Yes, Young People In Nursing Homes and I think we were going to be contacting Lyn. Is that right?

MS MORKHAM (YPINH): That's right.

MS SCOTT: We're now going to be bringing Lyn in on Skype. You might introduce Lyn to us.

MS MORKHAM (YPINH): I certainly will. Lyn, I'm not sure you can hear me there.

MR WALSH: We're still connecting.

MS MORKHAM (YPINH): I'll just briefly introduce Lyn. Lyn is a young woman who lives in a nursing home in Albury. I guess the reason Lyn is wanting to speak today with me is that her situation represents some of the gaps that I think this new system needs to address. Hi, Lyn.

MS SMITH: Hello.

MS MORKHAM (YPINH): How are you?

MS SMITH: Good thanks.

MS MORKHAM (YPINH): I was just talking about you. This is Lyn Smith, everyone.

MS SCOTT: Hello. This is David, Patricia.

MR WALSH: Hi, Lyn.

MS MORKHAM (YPINH): And John up the end. Can you see us all, Lyn?

MS SMITH: Yes.

MS MORKHAM (YPINH): Lyn, thanks for doing this with me. I've been talking with some other people from other organisations about the sorts of things we want the service system to do and Patricia, John and David have just been asking about how we see this system working and I was just about to say that your experience at the moment identifies, I think, one of the biggest ways in which we need to get the health and the disability system to work with aged care. If I can just speak a little bit, Lyn and then I'll get you to come in. Lyn, you've lived in the nursing home now for five years?

MS SMITH: Probably about four.

MS MORKHAM (YPINH): Four, sorry. I think Lyn went there when - her parents did support her at home. Lyn, do you want to just discuss a little bit about what's happened to bring you into the nursing home.

MS SMITH: I was having care at home and my dad was my main carer and I had nurses coming in in the morning to shower and dress me (indistinct)

MS MORKHAM (YPINH): Lyn, I'm just going to interrupt and say I think we've lost the signal a bit there. If I can just interrupt and say that Lyn has a disease called fibrodysplasia ossificans progressiva which is a situation in which the body's connective tissue and muscle ossifies or turns to bone.

MS SCOTT: Sorry, Bronwyn, can you just say again what happens to Lyn. Give the disease again.

MS MORKHAM (YPINH): This is a disease and Lyn was diagnosed with this when she was a young girl and so it's a situation which when the body is knocked or suffers any very minor trauma the connective tissue and muscle turns to bone. So Lyn is 34 and she's now in a position where she's frozen in a semi-reclining position. She's got the use of her left hand only. She was living at home, as she was saying. Her parents had supported her until her dad was diagnosed with terminal bladder cancer. Her mother couldn't nurse him and Lyn and she moved into a nursing home. Hi, Lyn, I'm just giving a bit of an update. We lost you there with the signal. I'm just giving a bit of an update on how you came to be in the nursing home.

MS SCOTT: Lyn, which nursing home are you in?

MS SMITH: Lutheran Aged Care in Albury.

MS SCOTT: Yes, I know Albury well; Albury girl.

MS MORKHAM (YPINH): So, Lyn, I'm just explaining how you are there. The biggest difficulty for Lyn at the moment - first of all, she didn't want to move into the nursing home. She wanted to stay in the community and I guess this is where we see a long-term care scheme being able to support somebody with Lyn's level of need in the community. I guess it comes to your comment, I think, Patricia or David, about how do we get the better links in with health and clinical. We were talking about that, Lyn, about how we get the different arms of the service system to work better together.

Lyn is a terrific example of how that isn't happening at the moment and where we think the scheme could work better, in that in a nursing home, the nursing home is not resourced. It doesn't operate for younger people with disability at all. Lyn needs some clinical input that they can't provide but she also needs some high level of support that disability services could provide but isn't able to at the moment because they see there's a demarcation.

MS SCOTT: So, Lyn, what would be the best set-up for you? What would you like to see a better scheme, a better arrangement, provide for you?

MS SMITH: Probably, like, more homes with younger people with disabilities. Like, I don't have anything in common with anyone from here. The next one up from me is probably, like, 60 years older than me. There's nothing in common. The nursing staff, like they're trained to look after the elderly but they're not trained in, like, you know, lots of things like handling the young person. They get intimidated because, like, a lot of them are around my age. They find it very hard to look after me.

MS SCOTT: I can understand, yes.

MR KALISCH: Lyn, what sort of number of people would you like to share with in a home or an accommodation arrangement?

MS SMITH: Probably, like, up to maybe 10 people if you had the amount of staff that could work with all those people as well.

MR KALISCH: So you'd see in that environment that you would have the opportunity to get together during the day?

MS SMITH: Yes, have a big, communal area where you can get together through the day and have activities and, like, go out, if you're able to do that, and just have people your own age that you can communicate with and do a lot of activities and that with, and even have a decent conversation.

MS MORKHAM (YPINH): If I could just interrupt, sorry, Lyn, to say that one of the biggest issues is that nobody at the moment is able to deliver the right level of support for Lyn so her disease is actively progressing because of the lack of training and input. So ultimately I guess this is the point; if we had a good lifetime care system, Lyn, you would be getting the support you need in the right place that would actually leave you with a greater level of independence than has happened because the nursing home is not trained to support Lyn's level of need.

MS SCOTT: Is part of the problem that Lyn is in Albury and not in Melbourne? I appreciate you saying that Lyn can't get the services she wants in Albury but would she ever get the services that she needs in Albury because it doesn't have a major teaching hospital - I mean, is it the medical services that are unavailable?

MS MORKHAM (YPINH): No, it's actually the support services that don't exist and it's the level of training around support workers. Lyn has got a level of clinical need now that disability support workers have never been trained to support. So we've got a whole new group - well, they're not new, they've been around for a long time - but there is certainly a growth group of people with high and complex needs with some clinical level of input that the disability system has never had to deal with before. It doesn't train people up to do that. People can be trained. So if we could train up the support workers we could get them to Lyn. Though, having said that, regional and remote areas certainly do suffer from less services, but it's not about that.

For Lyn, at the moment, it's about the demarcation between aged care and disability and the fact that disability services thinks it is actually doing aged care service by coming in and providing additional input to Lyn. So they literally will not do that. So they're leaving her in a situation where her disease is progressing more rapidly than it should have and she's worse off. So I guess the point there is to say that if we can get a better synergy between those service lines, if they can collaborate and work more productively, Lyn might come to the scheme for some additional input to provide support, trained support, at this point in time and maybe some community access and not a lot more because she is getting input from the nursing home to some degree.

MS SCOTT: Can I just check, if Lyn was in Melbourne would she still be in an aged care facility? She would.

MS MORKHAM (YPINH): Yes.

MS SCOTT: So if she was anywhere in Australia Lyn would still be in an aged care facility?

MS MORKHAM (YPINH): More than likely because disability services does not deliver the level and quality of care yet that people with these high and complex needs have.

MS SCOTT: Lyn, if you were in the United Kingdom would you be in an aged care facility, do you think?

MS SMITH: I don't know. I don't know anything about them.

MS MORKHAM (YPINH): England, I think, does have - they've got a very different notion of this where they have nursing level - they call them care homes, I think. Age isn't an issue there. People go in with a level of need. An interesting way of doing it but it's much more community-based in the local community. For us here in Australia and certainly from the Alliance's position, it's about going back to flexibility and choice. We need a range of options on the spectrum as innovative as the needs of the people who require them. Lyn said today that it wouldn't worry her to live with 10 people. We don't have any issue with numbers at all. Institutions happen with one person; it's not the numbers, it's the service, as somebody said earlier. So I think while the UK is often held up as the ideal, it has its own issues and problems too.

MR KALISCH: Lyn, we've talked a little bit about what services aren't available in Albury. If a better service was to be available in, say, Shepparton or Wagga Wagga or, say, Melbourne or Sydney, would you be willing to move to that location for a better service where you could live with people your own age?

MS SMITH: Probably not, because my family is all around this area and, yes, I've got all my brothers and sisters - my mum lives in Albury, all my other brothers and sisters bar one live within half an hour drive away and all my friends are here. So I don't think that I would move just to - like, I need that support of family and friends as well.

MR KALISCH: Thank you.

MS MORKHAM (YPINH): If I can just add to that; I guess that's a great example of why we need to have that collaboration. In this instance, providing an accommodation service for Lyn, the nursing home is doing a great job and it's something that she can't get anywhere else. So if we could bring in the disability input and support - and disability is saying, "No," largely because of funding - but if we could bring that in and work collaboratively with the nursing home, that would be a good outcome for you, Lyn?

MS SMITH: Yes.

MS SCOTT: Do you know of anyone else in your circumstances - would there be other people at other nursing homes your age, do you think?

MS SMITH: Yes.

MS SCOTT: So it's not impossible to imagine that there might be four or five - - -

MS SMITH: I know there is another female in the Mercy or Marianella. She's about 42 and she's in a nursing home. I haven't actually met her but I know of her through carers that I have and they've cared for her as well. A few others that are in a few homes around this area.

MS SCOTT: Lyn, thanks very much for joining us today. Very important that we got to hear about your situation. Thank you.

MS MORKHAM (YPINH): Thanks, Patricia. Thank you very much.

MS SMITH: Thank you.

MR KALISCH: Thank you.

MS SCOTT: Bye. Well, thanks, Bronwyn.

MS MORKHAM (YPINH): Thank you.

MS SCOTT: I was just saying as if by magic we're back on time. I can't put it down to good management by the chair but anyway, I'm pleased to say that we now invite Deborah Fullwood to come forward, please.

MS FULLWOOD: Thank you for the opportunity.

MS SCOTT: Thank you for coming along, Deborah. Could you state your name and indicate why you're appearing before us and then make an opening statement, please.

MS FULLWOOD: Deborah Fullwood, I'm a Sydney-sider and a parent of a couple of children including - both of whom are young adults, one of whom has Down syndrome and a hearing impairment and also wears glasses. He's 32 and I guess I've been rocking around the disability and family support area for many decades. I think this is a major opportunity for Australia to think differently around a system that has evolved over time through various pressure points. Some of the previous speakers have, I think, pretty eloquently described some aspects of that. I guess my thoughts today are really around the role of the system to support families and consider them within the needs as they may be assessed in this new system and to contribute, perhaps, a slightly different viewpoint.

MS SCOTT: Thank you for coming along. Deborah, what would you like to see in the scheme, and maybe you could relate it to your son's - I think son - circumstances.

MS FULLWOOD: Mm.

MS SCOTT: What would you see that needs to come out of a scheme for your family?

MS FULLWOOD: Well look, I think that the real difficulty is eligibility, and people have touched on that already. I guess I would be putting forward the view that families are important in people's lives and supporting the family unit is increasingly important, not just when children are young but in adulthood as well. We've heard from Lyn and Scott this afternoon. The way services can either support that notion of family centrality or in fact work against it is pretty critical. I think the bit part system that we've had to date often really works against families taking responsibility to the extent they can, feeling pride, feeling valued and working together with services. You often need to present yourself in a particular way to tick five boxes that get you into something or that indicate you don't have something else. That continual reinvention doesn't really allow you to get on with the main game, which is being a parent, being a family member.

I also think that families are very mobile. I know families are very mobile these days. I'm in a situation where my adult daughter's married an American overseas, she's not around as a sibling. Divorced, I'm in Sydney - my son has no funding allocated to him alone. So I'm sort of stuck in Sydney, don't dare pull out of what we've got, don't dare go back to Melbourne from whence I was born and where my extended family is. I've got a 94-year-old mother down there too whom I also support in some ways. So you're sort of stuck. I think you make - you make arrangements around what's possible. I think needs change at various points. It would be terrific to be able to say, "Well look, can't support that might be allocated to you happen somewhere over there where father happens to live and somewhere down there where mother happens to live," if you really want to talk about shared care. But without individualised funding and without the capacity to choose services yourself, someone ends up being the main carer. That's tragic for all sorts of reasons and all sorts of parties would agree with that, I think.

I think the uncertainty is also extremely debilitating for families, as well as the sort of reinventing yourself to tick the right boxes. The fact that you don't know whether there will be something around the corner - and I guess our family and son is part of a cohort that benefited from early intervention 30 years ago and has been at the sort of forefront of primary school inclusion and then secondary school and, you know, been at the forefront all the way along and is still at the forefront where there really is not a arrangements that really meet the needs of this young group of adults who have got fairly rich lives but who do need help, and need help of particular sorts.

So I guess I'm seeing a system that allows particular points of reassessment, which may be more and may be less, and maybe for quite short periods of times where additional support and additional activities might be needed for six months because there's some family event that will take attention and so stability can be supported through something additional; flexibility. I think there was discussion earlier around are we talking about a new system that's starting from scratch or are we talking about integrating what we have. I think we have to talk about integrating what we have. I don't think you can have a sort of a slow stream and a fast stream or an in and an out. I think we need to recognise that we do have infrastructure. It's about how that's accessed and can occur in a more flexible way.

MR KALISCH: I just have one question just based around your experience.

MS FULLWOOD: Yes.

MR KALISCH: You talked about the education system and your son's experience with that. The particular transition points or life stages that were particularly difficult and those that worked well?

MS FULLWOOD: Look, I think you're right, David, that looking at it in sort of a life cycle you can say, well look, you know, the early years and then primary school to secondary school are important points to get right. If they can be supported in a particular way then family structures perhaps remain more settled. The person themself moves into more confident arrangements and so the demand on the public purse is less as well. So I think there's win-wins all round. Some of them are pretty obvious in that way, you know, leaving school. Some of them are less obvious.

I think - I suppose I'm here to say that the fabric of life is a bit unpredictable and they might well be around other family members leaving home, which can be extraordinarily disturbing for some folk. They may well be around real sadness around the death of someone in the family. They may well be around an extend period having left school and the sort of familiarity of school that's not the challenge of moving on to new, exciting things but in fact almost a grieving. So I think families being able to work with services to think a little more in a more nuanced way around needs would be important.

I also think that there's - there will be a need, I know, with my son when he moves from his sort of current accommodation arrangement which, let me tell you, are a house of cards, an absolute house of cards. But clearly there will be a time when he gets dementia. He's got Down syndrome, we know that he is very, very likely to have dementia. The government has no sort of predictive attention to this group that stayed off the real radar of accommodation support. They're sort of almost unknown and yet they clearly are there and quite predictable as a sort of planned cost but no-one is really thinking about that. I mean if you're not on the radar then you don't have to be thought about. So the families that are creating a lighter footprint could be seen to have less needs and not in the severe and profound arena that is here and yet I'd be arguing that there's every reason to have their needs understood within this proposed arrangements to the extent we know what they might be.

MS SCOTT: Could you talk about the house of cards? I'm very interested to hear about that.

MS FULLWOOD: Yes, the house of cards. I'd also like to talk about sort of shared payments and co-payments. Currently the system makes it so difficult for people to feel confident about entering into some sort of shared cost that people just don't do it. My son's in a flat that's actually owned partly by my daughter who is overseas. She's got a sort of part-investment in Sydney, and I own the other bit because she couldn't afford it. So he's in there, pays market rent. It's a tax deduction for me because he's a tenant paying market rent. So some of the costs that I pay to support him sort of go through the tax man and out and back and that's smart. But I've been able to set that up. Not everyone else can do that and I quite understand that.

But you can't live in Sydney on the pension. Just can't live in Sydney on the pension. I couldn't have him living out in the boondocks somewhere, I mean I'm the support. So he has a job some hours a day, he has rental allowance, he has his income from the pension and he has income from his father and myself, all of which creates the pool out of which we organise this. But Centrelink says we can't - well, a family I know, I should perhaps say for the record - can't overtly arrange that income to appear as income or the pension will drop. Yet we're the ones that are creating the situation that reduces his demand on the public purse. So I have a brown paper bag I put money in and I pull it out every now and - I mean it's not what should have to happen.

I'd like to feel that those sort of co-cost contributions can be open and transparent and recognise that people can contribute differently. I'm very happy to do absolutely what we can, recognising the very dire straits that many, many people are in but I don't want it to be underhand and I don't want it to be an assumption either. I want it to be in a way that retains the right controls, I guess. There's a lot more I could say about that. He has a drop-in support person arrangement and they're hopeless, really. We've been through a few services. I guess the other point that I'd say in terms of measuring and thinking about eligibility is that I think there's sometimes a very simple assumption that people with mild intellectual disabilities have very minor needs, people with severe intellectual disability have very high support needs and people with moderate intellectual disability have somewhere in the middle needs.

I'd argue that group in the middle have much more significant needs because they're out and about, they're taking risks in all sorts of ways that people with mild disabilities aren't and people with very severe disabilities can't. The type of support they need is actually quite sophisticated, very flexible support that is very grounded in good staffing and management structures. Unfortunately often it's staff who are very well-meaning but really don't - you know, are not well supervised and not well managed and don't have a backup to the myriad of individual problems that arise.

He has been at one stage, not now, but he was wondering around Kings Cross every night drunk and the support service thought that was okay. They thought that was okay. They thought that's his right. I don't think it is. I think I know more than him on some things. I don't know more than him on lots of things but there are some things where I need to say, there's a line here which is we need to think about the skill level of support. So I guess severe and profound has a meaning in ABS terms but it also has a meaning in terms of risk and quality of life that I think would be useful to factor into your thinking as you move on.

I guess another point is just the debilitating effect of uncertainty too. I think some of the earlier speakers probably alluded to that a little, talking about somewhat predictable deterioration in health status but uncertainty about how that would be met. I simply don't know what the next steps would be. I just simply do not know. I don't know. That's not - it doesn't make it easy for me to plan my life and career and retirement, should it happen. So I don't see the service arrangements around that have sort of kept up with current experiences and thinking, probably, yes.

MS SCOTT: Yes.

MS FULLWOOD: Look, many mothers, particularly, I think, of young folk with a disability had very chequered careers, contributions to super have been minimal, haven't taken promotions, haven't been able to work in the ways that perhaps backup some of the choices that perhaps other people have. That's a gap that I think perhaps can be considered in some way in terms of measuring need. I don't know how you measure the need. I mean I'm - I leave those more erudite discussions to people whose life work that is. Certainly the old workability tables from long ago don't work. It's a very tough one. You've asked some questions in the papers around capacity to draw on future allowances and so on. I do think that adds to the flexibility. I mean clearly you need some sort of accountability controls around that but I do think - you know, it's not a linear path and some capacity to support what isn't a linear path would be a huge enhancement for people's lives and just for a better system generally.

MS SCOTT: If you - I'm sorry.

MR KALISCH: Yes, no, sorry.

MS SCOTT: It's all right. If you had an arrangement where funding was attached to your son and you and he were able to work through decision-making on that, would that resolve many of your concerns about the future and uncertainty and so on? Do you think the services that you'd be after do exist or is it the case that you'd have a little bit more control but you'd still be at the behest of maybe non-government organisations or generic providers who just are also just badly strapped for people?

MS FULLWOOD: Yes. Look, I think it would go a long way to answering some of the more immediate things. I suspect what might happen is you might have some families who choose to employ and manage staff themselves with expectations that they set up in a pooled way or something, rather than relying on the current real difficulties that many non-government organisations face. I think attached funding alone wouldn't address the degree of comfort that I would hope is around how co-contributions from families who can can be made in a way that's valued and respected and safeguarded without becoming a fight and an argument and a risk, really. For me that's another part of it.

MS SCOTT: Thank you.

MR KALISCH: Can you talk a little bit - I mean you gave us a bit of a sense about some of the difficulties of shared care.

MS FULLWOOD: Yes.

MR KALISCH: And some of the potential advantages of individualised funding in that context.

MS FULLWOOD: Mm.

MR KALISCH: Can you talk about sort of what would be a better system that would better enable people who wanted to have a shared care arrangement to actually progress that?

MS FULLWOOD: Yes. Well, I guess if you had funding attached to the individual and you had parents who were separated you'd be able to negotiate arrangements with services providers in two different areas that were both familiar, that talked to each other, that had sufficient consistency to make sense all round but recognised that they each had a role and neither was the sort of prime provider and that they were there to complement rather than take over. But that doesn't really seem possible.

I mean we did - we had some post-school options funding very briefly and we did attempt to have two post-school option services on the go in two different locations and there was a sort - one was the main recipient of the money and then they took another cut before the other one got some. It was just a bureaucratic nightmare. Joint planning sort of didn't really happen and it all just became too hard. But it was an opportunity, I kept saying, "There's a research paper in this. You're running a pilot project. Let's make this work." But no-one got terribly enthusiastic about it except me, really. But I think - I mean that's 10 years ago, probably, or more. I would hope that things have changed. I simply don't know. But I think if you want families to remain engaged then - families come in many shapes or forms. They have to be supported in where they've got to.

MS SCOTT: Yes.

MR KALISCH: Yes, I was quite taken with the points you've put about the contemporary family structures that we need to try and accommodate with any new arrangement.

MS FULLWOOD: Yes. I think siblings again are often quite fearful of being left with the lot.

MS SCOTT: Yes.

MS FULLWOOD: If they felt more confident around the uncertainties of the future they may well step in in different roles but they've got their eye on what's not happening too. So it's a bit like the insurance policy that you might need to call on and if it's there you don't need to call on because you know you could call on it. It's that sort of confidence that I think is very lacking.

MS SCOTT: Okay. John, are you - - -

MR WALSH: I'm good, thanks, Deborah.

MR KALISCH: Yes, I'm good.

MS SCOTT: Deborah, thank you for coming along. Is there any final point - you just want to check your notes that you've got through?

MS FULLWOOD: No, I don't think so. Very happy to talk further. I may well put in a submission when I - - -

MS SCOTT: Get five minutes.

MS FULLWOOD: Yes. Got my thoughts a little more together. Thank you very much.

MR KALISCH: Thank you.

MS SCOTT: Thank you.

MR WALSH: Thank you.

MS SCOTT: Look, we are keen to hear from Tony Abrahams but would you mind if we just took a short break, just a comfort stop, and see how we go? Thank you.

MS SCOTT: We welcome to the table Tony Abrahams. Tony, would you like to introduce yourself and make an opening statement?

MR ABRAHAMS (AIM): Yes, my name is Tony Abrahams. I'm the CEO of Access Innovation Media, also known as AI Media and with me is Leonie Jackson, who is the head of our education division.

MS SCOTT: Welcome both of you.

MS JACKSON (AIM): Thank you.

MR ABRAHAMS (AIM): We've prepared a few notes for you. I don't intend to run through them all, to give you the opportunity perhaps to ask questions. But AI Media is a social enterprise founded in 2003. Our mission is to deliver innovative access solutions that deliver inclusion for people with impairment. Our current focus is on delivering word-accurate speech-to-text solutions in real time that facilitate the inclusion of people with a hearing impairment in education and in the workplace. In fact the last page that we've attached for you is some media from the Sydney Morning Herald yesterday. I don't know if you saw that.

We've been in a pilot program with the New South Wales Department of Education since December 2006. I'll let Leonie talk a little bit more about that, because Leonie has got a lot more experience in deaf education than I do. But the principle behind it is that someone who is deaf can do anything except hear. Ultimately all we need to do is find a way to provide the same information to someone who is deaf as for those of us who can hear. The problem of providing inclusion for people with a hearing impairment has been pretty intractable for a long time. Sign language interpreting, as Carolyn is providing for us today, is pretty good in situations like this where you're having sort of conversations where people know the context and the content, but it's very difficult to try to explain new concepts to people in what is ultimately a different language to the language that you'll be expected to communicate with the general population in. I'll let Leonie talk a little more about that.

MS SCOTT: Just before you do, Tony, am I right in thinking that the system that you're supporting was the one that was on The New Inventors?

MR ABRAHAMS (AIM): Yes.

MS SCOTT: Yes, I - - -

MR ABRAHAMS (AIM): Did you see that one?

MS SCOTT: I did see that.

MR ABRAHAMS (AIM): Great.

MS SCOTT: Very impressive.

MR ABRAHAMS (AIM): Thank you. Look, we're not here to sort of spruik that particular solution but we do think that the Productivity Commission inquiry is a fantastic opportunity to actually look at what are the costs of not providing this particular service to people with a hearing impairment. But also it's an opportunity to take stock of the monumental shift in technology that is currently taking place that is actually allowing solutions like this that previously weren't even considered possible.

We actually estimate that - well, Access Economics did a study in 2006 called Listen Here where they've done ultimately what we hope the Productivity Commission will do, which is actually assess what the total future costs of inaction would be on disability and then look at comparing them with the costs of what action would be, in the sense of providing access and inclusion. In terms of deafness, the costs of excluding people from the productive economy were estimated around $12 billion a year. We know that deaf children now are 2.4 times less likely to even complete high school than their hearing counterparts. 160,000 people are out of work simply because they can't hear. Many of these are on the disability support pension.

We've estimated that the costs of providing access to education and employment for all deaf and hearing-impaired Australians through real-time captioning would be around 5 per cent of this 12 billion or around $600 million a year. The problem is that 600 million has to actually come from somewhere. At the moment we don't have a system of equating the future unfunded liabilities with the current costs. So at the end of the day that's really all we think we need to do, is actually have a mechanism to look at what those future costs are.

MS SCOTT: Thank you. Maybe we should hear from Karen now. Did you - have you brought along a copy of your segment on The New Inventors? Is there a way I can show my colleagues?

MR ABRAHAMS (AIM): If you're connected to the Internet there is.

MS SCOTT: I can go through iView?

MR ABRAHAMS (AIM): If you go to the ABC web site and search for AI Live you can see that sort of one-minute introduction, for what it is. It's also available on our web site.

MS SCOTT: Okay, thank you. Karen.

MR ABRAHAMS (AIM): Leonie.

MS SCOTT: Leonie, sorry. This is Karen.

MR ABRAHAMS (AIM): Carolyn.

MS SCOTT: Sorry, I've mixed it up, the end of the day. Sorry.

MR ABRAHAMS (AIM): Actually, could I just say one more thing, which a couple of the other people mentioned as well is - I'll just go through a few of these guiding principles. In terms of a pricing mechanism and the importance of ultimately redressing market failure, we believe that ultimately the issue of disabilities is a question of externalities not being appropriately priced into the mechanism, so therefore there are currently fewer incentives to redress disability than would otherwise be socially optimal. To ensure the integrity of the system going forwards we believe that service providers should be accredited to perform the services. We note that a statutory authority may well be the most appropriate body to do that. As the benefits of inclusion accrue to all in society we believe that funding any NDIS should be across as broad a base as possible.

One thing we did want to bring out that I think has been a bit missing so far in some of the literature around - set out in the disability investment group response is a focus on access and inclusion, particularly given the nature of the inquiry in terms of productivity. It's actually the lack of access, not the lack of care and support, that is the root cause of much of the exclusion of people with impairment. While many effective care and support systems deliver access, in some instances care and support systems deal with symptoms of exclusion, often the result of a lack of access in the past.

We believe that prevention also has a very important role to play and it's generally far more cost effective than remediating solutions. You can think of seatbelts, campaigns to quit smoking, but also turning down your iPods. That's a real, real problem. We gave evidence to the senate committee into hearing health on this. If we did have a national disability insurance scheme there would be incentives for the government to then actually look at this campaign and look at the effectiveness of a dollar invested in prevention versus remediation. We do think it's about getting the incentives right.

In terms of eligibility we agree a hundred per cent with what the previous speakers have said, is that arbitrary medical definitions of severe and profound should not deny eligibility to those who nevertheless suffer effective exclusion because of the level of their impairment. The cost effectiveness of providing access for those with mild or moderate impairment can be just as high, if not higher, than for those with severe or profound impairment. Ultimately we would say that the general principle should be that the NDIS should look at the effectiveness of each dollar invested in the system in terms of delivering inclusion and not on arbitrary medical definitions.

A word on technology is that technology will continue to make transformational solutions available at ever more affordable rates. We do anticipate a point in time where we wouldn't need a re-speaker in the middle of our system to allow us to generate accurate speech to text, but until then we do. So we need a system that is not going to lock in costs for 10, 15 years down the track but one that is subject to regular review and takes account of technological innovation. We also think that the NDIS is vital to support private investment in long-term continued innovation at delivering inclusion solutions and that social innovation practices can inform the design principles of an effective NDIS.

MS SCOTT: Thank you.

MR ABRAHAMS (AIM): I'll hand over to Leonie.

MS JACKSON (AIM): Tony has been talking about Access Economics, about how many people are out of work or don't have work because of a hearing loss. Before I have joined AI Media I was in the education - sorry, I was an educator for 18 years. I've taught many, many deaf students. My conversation with those students - and we were talking about their dreams for the future - it was not to be on disability support pension in their future but to be an actual taxpayer within society like the average Australian. But unfortunately the reality is that most of those students now are on disability support pension because they don't have enough access.

If you want to get support for employment, for example, then it's very difficult to get the right employer to accept deaf people into the workforce. They have some concerns about OH and S issues for that person, they're not sure about this, and so they can be very resistant to employing a deaf person. So what is missing is information, support, funding to provide those people with the support to become independent or to become independent taxpayers. I'm also the parent of a two and a half year old deaf son, so I'm always thinking about his future. I think - just the same as any parents, you know, what will his future look like down the track? What are my concerns? If the reality that's happening now continues to happen in the future then I'll have a lot of concerns for my young son's future because at the moment there is no enough opportunities for deaf people within the workforce, within the work environment. There's not enough access to good educational programs so that they can achieve skills and qualifications to work within different areas and within the community.

So I think that we need to look at - you know, what Tony was saying about is providing the appropriate support for those deaf people either through captioning or interpreters, whatever that may be to make sure that we have the funding to pay for this so that deaf people can continue to develop their skills so that they can take on promotions within the work environment. There are many people I have as friends who are deaf themselves who are working but they are worried about finding other job opportunities outside of the career they have at the moment. Usually you think, "This is the only thing I can get because I am deaf. This company understands my needs but there's no opportunities for promotion within this company," and so they have to stick on the same levels say for about 18 years to life. There's no other options to move to other companies or there's nothing that they can progress their skills on to. So deaf people are hesitant to look for other jobs because of the current situation in society and so they tend to stay within their current job for many, many years.

MS SCOTT: May I ask a question?

MS JACKSON (AIM): Yes, that's fine.

MS SCOTT: Leonie, you were an educator.

MS JACKSON (AIM): That's right, yes.

MS SCOTT: Realistically what other jobs and vocations were open to you?

MS JACKSON (AIM): Well, realistically - personally with my skills, really it was working for the Department of Education that supports deaf students. I don't think that I could have worked within mainstream schools, for example. The schools were not set up to accommodate a deaf teacher. I have the knowledge. I have the subject matter knowledge, I have the teaching skills, but that could not be transferred to work within a mainstream school system. So to be honest with the panel here today, my decision to jump over to AI Media, it was very nerve-racking for me because I was not exactly sure if I had the right skills for that job but I thought, "Okay, I'm going to really have to put myself forward here for this," because I had been within the same organisation for so long. I felt very safe there, they were familiar with me but I felt that it had been too long already. But for me to make the jump was very, very scary. I know that many of deaf colleagues were very shocked that I had done this. They thought, "Oh, Leonie's very brave to have made this move." I think that it's very important opportunity for deaf people within Australia that they're missing out on because of the fear.

MR ABRAHAMS (AIM): If I can just add there, I think Leonie is being a bit modest. Leonie's had 18 years' experience at the Royal Institute for Deaf and Blind Children supporting deaf students in particular in a range of environments both through the Thomas Pattison School there and also in other school environments. We've made certain modifications in the workplace to allow for deaf people. A number of staff, including myself, can sign. We have Carolyn, who is an in-house interpreter, but we also have the benefit of being able to use our own system, AI Live, which means that whenever we're having meetings we use the system.

Fundamentally we do believe this is transformational because it does open the door to mainstream corporate world for a lot of deaf people. We have been trialing the system with some major corporates at the moment who have had good records of employing deaf people and good inclusive practices. It's about awareness, it's about people recognising that there are solutions. Mostly from my experience people are willing to take that jump, if they know what it is, if you can give them that kind of awareness training and also if you have a system that actually effectively delivers that inclusion. People are pretty open to it, particularly when it's technology. The kids - I mean the fact that they can be cool and they're suddenly - without having a human being who might be their parent suddenly in front of the room signing to them, going through them, the teacher is actually able to communicate directly to them. They're seeing in English on their laptop exactly what is going on and they've got the notes after the class.

I actually - it was the final paragraph in this paper that really touched me, which was the comment from the support teacher, Sally Pape, who said that AI Live is improving these kids' literacy and that their grammar is improving, their written responses are improving, their engagement in the learning has improved and they've both shown themselves to be excellent students. Now, one of these students, the headmaster originally was reluctant to give the service too because he thought she wasn't smart enough. This one particular girl went from the bottom of the class to the top in 10 weeks because it's simply the difference between getting the information and not getting it. So clearly we think there's a case that needs to be made about a cost-benefit analysis for solutions, not just for AI Live but for solutions like AI Live that can harness the benefits of technology to deliver inclusion where it has not been possible in the past.

MR KALISCH: Perhaps a question for Leonie. From your experience is there a clear deficiency in the education system within the situation of deaf children not progressing through education to their capability and their interests?

MS JACKSON (AIM): Yes, that's exactly right. It's a harsh reality, for myself being a deaf person, to see so many deaf children not matching the same standards as the hearing children around them within their classroom. So I think that that's a frustration of many, many people who work within deaf education, thinking, "What is missing here? Why are they not being able to match their hearing peers?" I think that going back to what Tony had said earlier, if we provide the access - provide the access through these services - then they can think in the same language as the mainstream language of education.

For example, in high schools we know that English is the main language or the mainstream language but the kids are not getting the information within that language. They are going through another language. So imagine how difficult it would be if - say for instance we're doing an English test using French. It's impossible. So we're trying to do something with these deaf kids to - sorry, what we're doing is we are trying to teach these deaf kids to do the impossible - sorry, that was an interpreter mistake - so I think that what is important here is that we do recognise this, we recognise what is missing and basically we need to pull up our shoes and find out a better solution within education. That will then translate into the workplace. So if we have a good education we have good access, they think within the mainstream language, then that's a better set-up for their future employment and whole of life.

I had a few issues with the current set-up for deaf people within the workplace because for example, what is happening now the federal government have funding for employment assistance for workplace modifications. That's fine but it's only really suited for a small group of deaf people. So for example, myself, I work - in my workplace I would like my meetings to be captioned because that is the mainstream language, it is within English, but there is no funding available to help companies to pay for captioning. So it's only if a company has a good heart that they will provide that for their staff, is what I get at the minute, but for all the other companies and all the other deaf people out there that's not happening. So the guidelines at the minute say there's no provision to provide captioning for those who need it within their workplaces. So there's a lot of gaps at the moment that we could improve upon.

MR KALISCH: Is part of the challenge not just the technology but also changing people's perspectives and understanding? I'm thinking here also of parents of deaf children, that they have a broader vision and view of what their children can actually achieve.

MS JACKSON (AIM): I think that parents can only dream. They can hope that they have options for their deaf children. It doesn't matter what disability they have, obviously we all have these hopes, but in reality there's a big question mark over that. They don't have the same levels of options. The way that people in the communities think about disability, how they perceive them, are they employable, are they not, there's a lot of mis-perceptions, there's a lot of negative viewpoints on people with disabilities so that is something that we need to address before we can maybe see any improvement. Also, there's a lot of fears, like to people with disabilities themselves and also their employers have all this work - how can we work with a deaf person. There is a lot of uncertainty about this, so they don't know which path to take or which way to go.

MR ABRAHAMS (AIM): I think really it's reducing that fear.

MR KALISCH: Yes.

MR ABRAHAMS (AIM): That is going to have the greatest social impact, and having a system that just provides on a whole of life basis for what people need so that parents don't have to fear the exclusion for their kids. But also I think it's about having positive role models. It's about actually demonstrating success stories that can actually inspire parents to think about what might be possible in the future. I think that's what is great about this opportunity as well, is that for the first time there are actually stories in the newspaper about disability.

I haven't done an analysis of it but we've been in the sector since 2003, so seven years. I think for the first four years it was hard to find a single mention of disability in the newspaper. Then I think a lot of - Bill Shorten and a lot of the work that he has done has acted to raise the profile and certainly also the work through the Disability Investment Group has really started to raise the profile about something that has really just been in the too hard basket for too long.

We're certainly very excited about a lot of the developments that have happened. We had a huge cinema access win. I don't know if you saw that on the weekend. The major - well, up until - well, right now if you're deaf or hearing impaired or blind you have the choice of three session times a week to go to the cinema and you can see one movie for two weeks. Those session times are - when are they?

MS JACKSON (AIM): On Sunday afternoon, Friday night and a Wednesday morning.

MR ABRAHAMS (AIM): The deal that Bill Shorten help broker with the CEOs of the major four cinemas - and actually just getting them round the table and saying, "Guys, we need to think about this a bit differently" - is looking at a system whereby instead of having open captions, which is subtitles that everyone can see, the cinemas were understandably reluctant to do that because it hampers the viewing experience of the rest of the community. So they were looking for solutions that would allow a deaf person access but without compromising the rest of the film.

So there's a new technology called CaptiView that you sit in the drink holder. What it does is - kind of a bit like the microphone and you can actually see the captions in front of you. You can use it in any cinema. So within five years they were saying deaf people will have the choice of a thousand session times a day. So we've gone from three session times a week to a thousand a day because technology has enabled it and also there's a willingness from people to re-think disability. So I think awareness-raising is 90 per cent of where we need to go.

MR WALSH: Yes, thanks, Tony. I mean this is fascinating. I'm interested in your cost-benefit analysis, I suppose, and the number - there's obviously an assumption there of how many people would use AI Media. How many of those people could use a cochlear implant or hearing aids? Is there a relative merit between those and your system?

MR ABRAHAMS (AIM): Look, I think it's a great - I mean the way we would sort of categorise the solutions are there are medically-assistive solutions and there are technology-assistive solutions. It's a general misapprehension that as soon as you put a cochlear implant in you can hear a hundred per cent. People with cochlear implants often will still need services such as AI Live. In terms of who would choose AI Live versus perhaps interpreting over Skype - I mean that's obviously going to be a lot cheaper than having interpreters actually physically turn up to events. That's also another option.

We think that what - actually, if I can look at what we've done at school. We've tried to use the principles of a national disability insurance scheme in terms of how we've designed the system for the students. So what we've done is we've allocated them a certain number of hours, credits, if you like. We said, "We're not going to caption everything because you don't need captioning for PE. Why don't you tell us where you'd like - what you'd like captioned first?" They first chose English. They all chose English first. Then we went to geography, chemistry and biology. It's working for all of them and the results are - they're improving their results for all of them.

The assumptions that we've made are based on 12 and a half hours a week of captioning at school. At university you would need to caption everything but we're actually in discussion with some very forward-thinking universities who recognise that once you've generated this text it can be available to everyone, a bit like wheelchair ramps, really useful for your strollers and your - - -

MR WALSH: Well, automatic transcripts of lectures.

MR ABRAHAMS (AIM): Yes. Then you've got the transcripts available afterwards.

MR WALSH: I'm thinking more about - I mean captioning is fine in the classroom or in university or in a meeting room in a workplace. What about lunchtime when you need to go and buy a cup of coffee at a restaurant? I'm just thinking of the relative merits of a medically-assisted device versus a media in situ thing.

MR ABRAHAMS (AIM): Sorry, I - if I was in any way negative about a medically-assisted device I was not intending to be. I think they're essential kind of thing. I think it's absolutely imperative that medically-assisted devices be funded as well. I think though it's important to recognise that people will often need both. Again, it's - I just approach it from the perspective of what do you need to get access? If a hearing aid actually gives you effective access to what you need and you've got appropriate workplace modification through deaf awareness training, then you might not need captioning in a lot of situations. Carpenters might be able to get by just fine or - you know. But in a - and actually, Leonie is generally fine on a one-on-one or a one-on-two situation but beyond that it becomes quite difficult.

We've been taking expressions of interest since we launched the service - which has only been since April. I mean we've only launched the service in April. Most people who are looking at participating in the pilot for work - they've only wanted the service once a fortnight. The rest of the time they're actually managing to get by. So I don't think the costs are actually going to be that huge beyond education but it's really education where it's going to be critical, I think. But I know you have a different opinion on that?

MS JACKSON (AIM): Yes, I do agree with and also - sorry, just to go back slightly. After we launched AI Live, I think I was a little bit taken aback by how many deaf and hearing impaired people with cochlear implants and hearing aids contacted me and said, "Oh, this is what I want for when I go to my work meetings," because up until that point they have been trying to hear through the cochlear implant but not to a hundred per cent and there were things that they were missing. It creates a lot of frustration for them because they're missing out on crucial information in order to do their job well, so that can hold them back.

So I feel or I know that myself when I was in mainstream school there is no support within the education environment and it was a very, very stressful time because I was always worried about missing out on information. So I can imagine that this is the same for the people with the cochlear implants, that they are missing vital information and there's no way of getting that information, because people just move on with the meeting. So I think that it's important to realise that even if you have a hearing aid or a cochlear implant there's still a lot of things that you miss out on. You can miss a lot of information. So that's why I wish I had this solution in my workplace or when I was studying at uni.

Another angle to think about too is sometimes when a signing deaf person thinks, "Oh, I've got an urgent appointment," or, "I have to go to a specialist doctor," there's no time or availability for interpreters. They will say you can book them - sorry, in the future we'll be able to do this on the mobile phone. So for instance, I can book a captioner who could caption the appointment there and then for these immediate appointments with the doctor when you couldn't get an interpreter. So there's a lot more scope for AI Live or for other captioning services within sort of different angles of life.

MS SCOTT: Okay.

MR WALSH: That helps. Just one more question. The captioning, is it feasible sometime in the future where that may be electronic?

CAROLYN: Sorry, where it might be?

MR WALSH: Electronic.

MR ABRAHAMS (AIM): Or automatic.

MR WALSH: Or automatic.

MR ABRAHAMS (AIM): Look, there's what we call two different types of speech recognition systems at the moment. One is speaker independent and one is speaker dependent. Now, speaker-independent speech recognition systems are when you might try and order a taxi. You know if you've ever tried to order a taxi that sometimes it gets it right and sometimes it gets it wrong but it's generally pretty good where it has got a limited database of entries. So there are on 440 suburbs or something in Sydney so it knows that when you're saying St Ives it's quite different to sort of Bondi or something like that.

Google have actually got an automatic speech recognition system that you can use on YouTube to generate and sort of auto-caption, they call it. It's about 80 per cent accurate. Now, that actually sounds a bit better than it is. So that's speaker-independent speech recognition. Speaker-dependent speech recognition was at about 92 per cent accuracy about 15 years ago, and that was useless. When you're getting one in five or one in 10, or even one in 20 words wrong and you don't know which word that is, it becomes unintelligible pretty quickly.

The other thing that speaker-independent systems don't do is put in punctuation. If you try and read a piece of text without punctuation or without knowing the context of something in terms of whether it's, "The sky is blue," "I blew my nose," or, "I'm going to the Blue Mountains," for example, it's very, very difficult to follow. Do I think one day these problems will be solved? Yes. So ultimately this is a temporary solution. So at the moment we're just at the point where speaker-dependent speech recognition is good enough. We've actually just got there about three years ago. We use Dragon NaturallySpeaking to plug into our AI live system. Dragon version 7 - I'm happy to go on the record with this - was useless, but Dragon version 8 was great.

Suddenly it was that technological leap between version 7 and version 8 that made it really good. We're up to version 10 now and we can get accuracy levels - with people who we train to speak in a fairly robotic way, with the punctuation, and you have to put paragraph marks and all that kind of stuff in, then we're getting 99 per cent accuracy from those people who can listen and respeak at the same time, which incidentally is an aptitude. It's actually something that you seem to be born with and seems to be hard wired; so you can either do it or you can't. We're finding about one in three people have that aptitude to be able to do it. So there's quite a large pool of potential people who could do it.

The model we're looking for in terms of social innovation is actually where we can get local communities to support local students using a global platform and global sort of skilling system. We would train and accredit those people to provide local solutions, because local knowledge, at the end of the day, is what is critical to providing effective access, because as Leonie alluded to, if you don't understand the content then you can't provide the access. I think it's still a fair way away before that can be completely automated, although an NDIS should allow for the possibility - when it is possible then that's - the funding levels should reduce to make - and should be spent somewhere else.

MS SCOTT: Well, thank you very much for attending today. Thank you to Carolyn and Leonie and yourself. Thanks, Tony.

MR ABRAHAMS (AIM):   Thanks for having us.

MR KALISCH: Thanks very much.

MS SCOTT: I now invite anyone who wants to say anything to come forward. We'd like you to keep your comments brief. Please come forward now. Welcome, Michael, to the table. Could you state your name and indicate if you're representing yourself or an organisation, please?

MR HERDMAN: Myself. My name is Michael Herdman and I'm representing myself.

MS SCOTT: Yes, okay, thanks, Michael. What key points would you like to make?

MR HERDMAN: So what I'd like to do at this time is I'd like to come up with a solutions for the benefit of the panel in order to assist you.

MS SCOTT: Thank you.

MR HERDMAN: First off I'll give you a bit of background, if I may. I received my initial diagnosis about my intellectual disability back in 1953. I received my final diagnosis in 1955 and I was almost committed into Callan Park when I was a child, unfortunately. But fortunately for me - my parents (indistinct) that's where I would have finished up. I've been fortunate enough to remain out in the community. I'm now subsequently a member of the CID board of directors, which is the Council for Intellectual Disability New South Wales. I'm a foundation member of People with Disability in Australia. That was formerly Handicapped Persons Alliance. That was based on an organisation called (indistinct) which is (indistinct) members Association. From 1956 - I joined that organisation in 1956. I subsequently was elected to the board of People with Disability in 1997; chairman till 2001 where I'm now a life member of that organisation. I'm also serving on the CID board of directors.

MS SCOTT: Okay, so you're well credentialled. So what would you like us to know about the future scheme as you think should be - - -

MR HERDMAN: What I'd like to do (indistinct) future needs of people with - not only people with disability but also people who acquire disability in their lifetime are concerned for the - are current members of the ADF at the moment. Why should - who are currently injured during their service they are subsequently discharged from the armed forces. What I'd like to see happen is - they haven't been catered for as far as rehab is concerned and also retraining subsequently. Also I'd like you to deal with asylum seekers in regards to help them, should they acquire an intellectual disability during their detention. I have a mild intellectual disability at the moment. Subsequent - I was diagnosed when I was a child.

MS SCOTT: Okay. So if I've got it right, Michael, you're interested in rehab and in retraining.

MR HERDMAN: Yes.

MS SCOTT: Okay, those are two key things. All right, thank you for that. Would you like to - any other area you'd like to point to?

MR HERDMAN: Subsequent - too much in the past the government is relying on input from bureaucracy alone. I do believe that is inadequate. I do believe that the bureaucracy is not sufficiently experienced to address people with disability - I don't believe the bureaucracy is sufficiently qualified to address the needs of people with disability.

MS SCOTT: Got that, good. Okay, all right. David, do you have any questions?

MR KALISCH: No.

MS SCOTT: John, do you have any questions?

MR WALSH: No, thank you.

MS SCOTT: Thank you very much.

MR HERDMAN: I'd also like to thank the panel for this opportunity to address you. I hope you have a vastly successful - I hope you have a successful Productivity Commission and thank you very much.

MS SCOTT: Thank you.

MR KALISCH: Thank you, Michael.

MS SCOTT: Well, I now adjourn the hearing for today and we'll resume tomorrow. Thank you. Thanks, Michael.

AT 4.24 PM THE INQUIRY WAS ADJOURNED UNTIL
WEDNESDAY, 21 JULY 2010