PRODUCTIVITY COMMISSION

DRAFT REPORT ON DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT PERTH ON WEDNESDAY, 20 APRIL 2011, AT 8.54 AM

Continued from 18/4/11 in Adelaide

INDEX

MS SCOTT: Welcome to our public hearings on the draft report, the inquiry into Disability Care and Support. You are very welcome here. We will try and run today in a timely way, but hopefully in a way that makes you comfortable about presenting your material. Are there any representatives of the media here at present? No. Okay.

We have a busy schedule and we have allocated people hopefully sufficient time for them to present their points of view in response to our draft report. If it turns out during the course of the day you feel you'd like to make some comments but you are not officially on our schedule, I'll allow some time at the end of the day for people to come forward, if they wish, to make a few brief comments but I might ask that you keep your comments to five minutes, otherwise we could be here for quite some time.

We'd like to conduct the hearings in a reasonably informal manner, but I do remind participants that this is not a public meeting and that we are actually making a recording for transcript purposes, so we won't be taking questions from the floor. But, as I indicated, if you do wish to come forward and make a remark, please do so at the end of the day, when invited.

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 make comments on recommendations or on their observations and of course we are inviting submissions from the public and from organisations by 30 April, as we have to complete our report by 31 July to the government. I can't indicate when the government will release our final report, that is entirely up to the government itself. If you wish to follow the hearings we have had to date, they are available on our web site at pc.gov.au and you'll be able to follow, with a few days' lag, where the hearings are up to.

I now invite Andrea Simmons to come forward and present her material. Andrea, I'll just explain to you and to everyone else the arrangement here. Like last time, we have got John Walsh, the associate commissioner for the inquiry, on Skype and on telephone. So don't be concerned if suddenly John's happy face disappears, he still can hear you. Hopefully this will work well. It has worked well in all the other locations we have used it, and I think it worked fairly well here last time.

Andrea, welcome. Could you indicate the organisation you're representing. We have allowed 30 minutes for your presentation, but if you could think about the fact that John and I are likely to have some questions, that would be good.

MS SIMMONS (DANA): My name is Andrea Simmons. I am the chief executive officer for Disability Advocacy Network Australia. That's a peak organisation, a representative body for disability advocacy organisations across Australia. We have

59 member organisations that are in every state and territory. Our member organisations include those that provide systemic advocacy; advocacy for individuals; what is called citizen advocacy, which is advocacy by volunteers on behalf of or alongside individuals, but supported by the advocacy organisation; family advocacy organisations, which focus on supporting family members to advocate for their family member with a disability; legal advocacy organisations; and those that do specialist advocacy type work, for example multicultural advocacy organisations that really look to the needs of people from non-English-speaking backgrounds.

We will be putting in a broad-ranging submission to the inquiry that will cover a lot of areas of the report. However, today I wanted to focus specifically on advocacy because that's an area of the report that the DANA membership believes hasn't been well addressed, and because we have some very specific things to say about how we think advocacy should be a part of the overall system of supports for people with disability. I suppose the first thing to say is that because we are advocacy organisations we strongly believe that people with disability need access to advocacy support independent of the advocacy support they might be able to receive from family members, from friends, from service providers and others.

We would hope that across the system and within the community at times there will be people that will take up the role of an advocate for someone with a disability. But our organisations actually have a particular place, in that we are able to be independent of all those other aspects of a person's life. That means that the independent advocacy organisations can absolutely focus on the needs and wishes of the individual rather than, as service providers have to do, looking across all the people to whom they're trying to provide services, and rather than family members who often will have to look to the interests of all the members of the family, not specifically the person with disability.

In no way do advocacy organisations expect that they're the only ones doing advocacy, what they try to be though is an independent voice for people with disabilities. What we say about that is that in any system you're going to need people who can point to the things that are not working in a system and that for a system to function well you need people who will be able to be fearless around that, who don't pull their punches, who don't stand to lose their funding because they are being fearless and saying what needs to be said.

There are many people who are vulnerable because of their disability or because of the way the world looks at their disability - and not all people with disabilities are vulnerable, we are not saying that in any way - and that vulnerability will often lead to the need for an advocate, someone to either assist them to put forward their views and support them in doing that, or, alternatively, to actually speak for the person where that is required. Our concern with the report was that we saw in it I suppose a lack of understanding of the role of advocacy in supporting people and the independence that was required.

Because advocacy support will be needed commonly to advocate in relation to the services and supports that are being provided, will be needed to advocate in relation to the assessment that might be done by the NDIA, will be needed to advocate even for services and supports to be provided, for all those sorts of reasons, we see the advocacy actually needs to have mechanism for funding and administration that is somewhat separate from the NDIA. We have a particular view about that that we have put forward over a number of years and which is supported by advocacy organisations across the country, and that is that what is needed in terms of the administration of advocacy is a separate statutory authority that takes it outside of the administration of the service provision for people with disabilities.

What we have seen over the years, where advocacy has largely been funded by the same arm of government that funds service providers, is that the provision of funding to advocacy has been largely held stable, while service funding has grown dramatically over the last 20 years to meet the need; we are not indicating that service funding ought not have grown, quite the contrary. But what we are saying is that advocacy hasn't been given the same weight. One would say that where the numbers of vulnerable people are growing we ought to be seeing advocacy support grow as well, over time.

MS SCOTT: Just a point of clarification. You said that funding had been growing to meet the need. Is that your view, that in fact needs are being met?

MS SIMMONS (DANA):   No, it certainly isn't our point of view.

MS SCOTT: I just wanted to clarify that.

MS SIMMONS (DANA):   It is, however, our view that there has been greater attention paid to funding services and supports for people generally than there has been attention paid to funding advocacy support for people. So that's the point.

MS SCOTT: I understand the point.

MS SIMMONS (DANA):   No, we certainly view the system as not currently catering appropriately for the needs of people with disability and it not being funded sufficiently to do that. We have suggested and we will be putting a more detailed submission around what we see as appropriate in terms of a national statutory authority for advocacy. We do, however, recognise that the proposals around the National Disability Insurance Scheme and the funding of that is something that is actually probably going to be the dominant source of funding for disability services and supports into the future.

We see that what would be an appropriate mechanism for the funding of advocacy is for there to be a formula arrived at that could deliver a proportion of the money coming in to the NDIS that would then be dedicated to advocacy and provided to our proposed statutory authority for the administration and funding of independent advocacy organisations. We see the benefits of that as really taking away to some extent the politicisation of the funding of advocacy.

There is no doubt that has been an issue over many years, that where you have a minister or a department in a particular government that is for some reason more in favour of advocacy then advocacy organisations have done better; and where you have a government that really doesn't enjoy advocacy very much, you have seen advocacy organisations do very poorly, and to a much greater degree than the general service funding, because there is more bipartisan support I suppose around that. So by trying to establish a linkage which we think would be an appropriate linkage to the funding coming in to the insurance scheme, we could thereby ensure to some greater extent that advocacy is appropriately funded for the future.

There is one other set of issues I could address, and that is that it's quite clear that the funding for advocacy isn't something that can easily be individualised in terms of how people pay for it. That is because in lots of cases advocacy is on a systemic level, and so you can't take something from a person's individual bucket of money or individual entitlement to fund that. Advocacy commonly gets involved before people have access to any entitlement, it's commonly involved in assisting people to access an entitlement. So there's no possibility there for an entitlement in the first instance to provide for that.

Advocacy gets involved when the services and supports in a system aren't working well for somebody, where there's an issue. It would be inequitable for someone who already was receiving inadequate services and supports to be actually required to pay for advocacy to redress that situation where someone else who was getting service and supports that met their needs and wishes appropriately didn't need to put aside part of their entitlement for that. You would also see advocacy not stacking up well where people have high support needs and are desperate for personal supports, things that allow them to live to live an ordinary life, and yet if they were able to put aside part of their entitlement for advocacy they would do much better. But it's not something that actually automatically occurs to people.

Particularly, you would find that where you have guardians involved and where a person's needs and interests are actually in competition with the guardian, you're not going to see a guardian agree to part of the entitlement being used, and essentially you'd have an argument with them. So there are all sorts of reasons why funding for advocacy from individual entitlements doesn't really make sense. That's another reason I think that supports the notion that advocacy generally needs to be dealt with differently by the system.

MS SCOTT: Thank you very much. John, do you have some questions for Andrea?

MR WALSH: Thanks very much, Andrea. Yes, I do have a couple of questions. Andrea, I'm just looking at your submission from August last year which talks about the sort of tasks that are taken on by independent advocacy organisations. Those tasks I think would be most important in a system such as we have at the moment, but I think people agree it is a broken system. I'd be interested in your views on how those tasks might effectively phase themselves out over time, if we can achieve the sort of system where community integration and funding levels are much better than they are at the moment.

MS SIMMONS (DANA): I suppose our view is that no system will ever be perfect. No matter how much effort you put into making it so, there will always be issues that arise, not the least because systems are undergoing constant change. While we hope that the Productivity Commission, together with the government, can produce a perfect model, we have never seen it happen yet. So I believe there will always be a role and place for systemic advocacy. People with disabilities who have significant cognitive impairment, people with disabilities who are experiencing an environment which is not disability-friendly, will always be in need of support to address those issues. Whenever people are feeling vulnerable, they will be in need of support to address issues that are affecting them negatively.

While you might have a system that is working well on a large scale, individuals will always come up against other individuals who are not performing in the way that they should, they'll come up against services which for some reasons have taken a wrong turn in terms of the way that they are providing their supports and services. So I can't see that we will ever have a situation where there isn't a need for advocacy support to respond to those kinds of things. What you might hope to see is that the community at large would take on a greater role in stepping in where things are going wrong for people. But I would say that the community we are in at the moment is a long way shy of being good at that and being prepared to do that; and if it were to happen, I would be one of the first to cheer.

MR WALSH: You mentioned this morning that you would advocate a proportion of the funding for the NDIS to be set aside and apportioned to an independent statutory authority which had an advocacy role. Have you given any thought to how much funding would be required for independent advocacy?

MS SIMMONS (DANA): We have certainly given thought to how we might suggest a structure that you would try and seek to fund. So looking at what you would expect would be reasonable in terms of funding available per head of people with disability for individual advocacy, for systemic advocacy, that kind of thing. I'd have to say that our capacity to produce figures in that regard has been fairly limited to date. But what we would be hoping to do is suggest some principles by which one could construct an appropriate level and mechanism, and we will be seeking to do that for the submission that we make.

MR WALSH: Thanks. I just have one more question, Patricia. I would appreciate a comment from you on the balance between advocacy and litigation, and I suspect it depends on skills of the individual advocate. I have experienced and have had reported to me situations where the advocacy process ended up getting a worse outcome than if the advocate had never been involved in the first place because it becomes an adversarial contest. Have you got any comments on that?

MS SIMMONS (DANA): Good practice in advocacy is generally about trying to resolve the issue closest to its source and in a way that will have the most minimal impact on the relationship, or at least lead to still ongoing positive relationships between the person with disability and those with whom they have an issue. At the same time, you can't always do that. Good advocacy actually is about seeking to resolve an issue; if you can't do it close to the source, then you move it to the next stage, and so on. You can't always as an advocate know how the other side of the argument is going to respond to what you do. So in any situation the people making the decisions are actually making their best guess about what is likely to lead to a resolution.

Good advocacy practice is where the person with disability is able to and wishes to make the decisions about what happens themselves . Largely, the advocacy is driven by the person with disability themselves. Advocates commonly get blamed for giving poor advice, when what they have done is given a range of options to somebody, and then the person themselves has decided the way forward. That is what happens in the ordinary community. People don't always make the best decisions for themselves at any point in time. In hindsight, people can look at what has occurred in any sort of situation and say it could have been done better.

The other thing that needs to be taken into account is that advocacy, like any other area of work, actually benefits from an input in terms of training and connection with other people that are conducting the same kind of work. There has been very limited funding put into the system to support advocates to do their work in a connected and experiential way. We would certainly say that this is something that needs addressing for the future. We would hope that the Productivity Commission would support a level of funding for advocacy organisations that allows for appropriate training and appropriate professional development alongside other advocates.

MR WALSH: Thanks, Andrea.

MS SCOTT: Andrea, I want to direct my questions in two areas. One, is to this area of advocacy and how we can better reflect the need for advocacy in the final report. The other area is mental health because I want to give your subconscious a bit of time to be thinking about the mental health issue. So now back to the issue about advocacy. You made the distinction between individual advocacy and generic advocacy, and I just want to explore that a little bit more. John and I and the team were thinking about the need for someone in a person's corner, someone looking after them in a variety of ways, when it came to the assessment process or at different stages of life and in terms of understanding a new system and feeling comfortable with that and rights of appeal and merits review and so on, but we probably didn't think about generic advocacy at great length.

So I'd like to just check that you're comfortable with the idea that while there is a need for generic advocacy, there's also a need for local people on the ground, often in meetings with service providers and in the assessment process and after the assessment process, who really have the direct interests of that individual rather than thinking about the scheme as a whole or other issues. Are you comfortable with the individual role of advocacy that we have in the draft report?

MS SIMMONS (DANA): I may have misunderstood what is in the draft report in the sense that I see that the report proposes that there would be disability support organisations and people who have a role in sort of a case management arena. It doesn't, to my mind, reflect really what you have just suggested, which is someone who is in the person's corner and only in their corner. So we would say that that needs a greater explanation within the report. I suppose our other problem is that really advocacy in the report has been aligned with disability support organisations, where we would see that the function is somewhat different. Disability support organisation is still about the structure of the service and - - -

MS SCOTT: I just want to interrupt you there. I'm not trying to diminish the importance of generic advocacy, I think I have got your point, and you made it very well today, and John and I have heard this point made a number of times during the hearings. I just want to check though on individual advocacy. I know one of your organisations may take up a particular issue and you have mentioned people from culturally-diverse backgrounds, they might suddenly think that there isn't sufficient attention paid to that, or that a particular regional office might have an arrangement that doesn't seem appropriate for that area. I can understand that is sort of a generic issue. But in terms of an individual person, did you have any issues with the idea - besides clarity - that someone would be able to be in your corner, if you wished, every step of the way if that's what you wanted?

MS SIMMONS (DANA): That's absolutely what we would like to see available for somebody. Beyond that, we need that possibility not only when you're engaging with the NDIA, but also if you're engaging with an assistant delivering education or housing or health. So advocacy needs to be - and that support, that person alongside you and assisting you to put forward your interests - available for very vulnerable people in all the aspects of their life where they're engaging with systems or with others who might not be prepared or interested in taking their interests into account.

MS SCOTT: Okay, that's good. On generic advocacy, would it be possible for you to tell us in broad terms - not down to the second decimal place or anything like that - what funding is currently available to your 54 organisations through the federal and state governments, if that's possible, in broad terms. Not off the top of your head now, I'm happy for it to be a question you'll come back to us with in writing. It would be quite interesting to know what that is. I think John was after the magic percentage and just to have some sense of your workload, if there is any way of measuring that, that would be very good.

Just a clarification. You did make the point - you made it well, and a number of other people have made it - if a package is inadequate, suggesting that someone takes their inadequate package, to pay for advocacy didn't sound right to your organisations. I think this is where John and I need to be clearer. The idea is that people have adequate packages and that if they want to have someone in their corner helping them negotiate their way, in addition to their local case manager - I guess, in local lingo, a local area coordination person - then that would be on top of their packages. It's not as though you'd have to give up the wheelchair because you decided you wanted to have a DSO. That was never our intention.

MS SIMMONS (DANA): Yes, there's a few different things mixed in with what you have said. Where you have organisations that have to distribute resources in a way that is thought to be equitable and they have a limited bucket of resources, then you will find that there is a mechanism that goes on that is about encouraging people to downplay their needs and discount some of the things that they would otherwise say that they wanted for engagement in an ordinary life.

I have real trouble accepting the notion that we would get a system that actually meets people's needs wholly and solely, especially in the first instance, because we live in a world where funding is rationed and people with disabilities know that better than almost anybody else. So to expect that we would end up with a system where everyone got what they needed I think is still a fairytale which we would love to come true. So you need people that sit outside your system mechanisms for delivering services to actually be alongside somebody. The way local area coordinating has worked in the states, that I have been aware of, they are still about rationing scarce resources. So they are still about making choices about what people will get.

When we look at advocacy, the independent advocates are never involved in that level of decision-making. When they are working alongside somebody their sole purpose is to ensure that that person's voice and that person's interests are what is going forward. So that's the problem I suppose that we have with the notion that someone like a local area coordinator, someone like a brokerage agency, someone like a disability support officer, from what I have seen in your report, would actually be able to focus on that person's interests alone. We have trouble believing that, from where we sit, in a system that we have seen to date and with local area coordination, for example, that we have seen to date.

Likewise, it has been put to me very strongly by some of my members that one of the things that we are likely to see in the future with a National Disability Insurance Agency is that part of their role that they will see that they have is to drive costs down. There are a number of ways of driving costs down, but one of ways is that you actually diminish the amount of someone's entitlement and you do it on a justifiable basis and you do it in a way that suggests that prices for services have come down and that the system is actually working in a way that has created competition that has caused that to happen. But we have never seen that that has worked beneficially for people to date.

We have to have the opportunity of seeing a system that actually does respond to people's needs and isn't all about saving money and isn't all about getting a minimum amount that will just be about survival. Until such time that we actually get a system that is better than that, we would not accept that advocacy is not going to be needed in there to actually make the case again and again that people aren't getting what they need.

MS SCOTT: I understand. That's a good point. Could I now go to mental health. I know we are going to just stretch over time, but I'll make it up by having shorter morning tea. Your organisations advocate in the area of mental health. One of the difficult questions with which John and I and the team have been grappling with is we acknowledge that mental health services in almost all jurisdictions are not sufficiently addressing need. We know there's many unmet needs out there. But where is the appropriate delineation between the disability sector and the mental health sector?

We have tried our hand at some ideas in the report. Does your organisation have a view on this? Maybe I'll take your personal view, if you'd like to offer that. If you don't have a view today, could I encourage your organisation to give consideration to that, as we are looking for as much input on this difficult issue as possible. If you're not familiar with what we have said in the report, I am happy to refer you to the sections that are relevant.

MS SIMMONS (DANA): I have read it. Look, we have a preliminary view, subject to final approval. That is really that the UN Convention on the Rights of

Persons with Disabilities talks about people with psychiatric disability as integral to the rights that people should be able to access. Many of the organisations that DANA represents actually provide advocacy for people experiencing mental health issues as part of their disability advocacy funding. So you would see that at least for those organisations they don't distinguish between the types of disability, they just look at what people need and go forward from there.

I think the principle that the commission has outlined in its report around the NDIS not taking the place of and not fulfilling the responsibilities that rightfully belong in other places is a valid one. It's our view that the health system should actually respond to the health needs of people, whether they be people with disabilities or other people, and that goes for people with mental health issues.

However, flowing from their health needs people do develop core activity limitations, and where someone has developed a core activity limitation - that's using your terminology, I think - that flows from their health need, whether that be mental health or whether that be some other chronic health need, then we do think that the National Disability Insurance Scheme should be covering their needs insofar as they are about living in the community but not insofar as they are the health needs that should be being managed by the health system. So I don't think we are actually out of step there even with NDIS, which is something that advocacy organisations can't always say.

Beyond that, what you would have to do though is look to where the funding is in the system currently. So you would say that if the NDIS is going to pick up responding to the needs of people with mental health issues where those needs are not specifically their health or clinical needs, then there are already buckets of funding that aren't related to disability at the moment that are directed to that; for example, the Personal Helpers and Mentors program, at the national level.

So you would be suggesting that it's not just the money that was in the past involved it the national disability agreement that should go towards fulfilling the responsibility of the Commonwealth in providing for the NDIS but also that there would be some areas of the current mental health bucket that would belong then with the NDIS. But we would see it making much more sense to delineate people's needs in that way, that the health system deals wit the clinical health needs of people and that the NDIS deals with the needs that people have arising from their core activity limitations, howsoever they were produced really.

MS SCOTT: Thank you very much for coming along today. We look forward to getting your submission.

MS SIMMONS (DANA):   Thank you.

MS SCOTT: I now invite Carers WA to come forward, please. Good morning and welcome to our hearing. Please don't be concerned about John's happy face not appearing on the screen. We are having a little trouble with Skype this morning. He actually is on the telephone, and so he is attentively listening in to our hearings today.

MR WALSH: I'm here.

MS SCOTT: That's right. Thank you for coming along. We have allowed 30 minutes for your presentation. For some reason, I have been able to get back on track in terms of timing, so we're okay. So over to you. Would you like to make an opening statement? Could you identify yourself for the record, and then just allow some time for John and I to ask some questions.

MR COATES (CWA): Thank you. My name is Paul Coates. I'm the CEO of Carers WA. With me today is Nola Kennedy, who is the carer of a person with a disability. Nola will be saying a few words as well, after myself. Sandra Collard, to my right, is from the Aboriginal HACC, manager of People Who Care, and Sandra will be speaking at the end of the presentation. Obviously, Nola and Sandra are particularly going to talk about Aboriginal issues. Carers WA provided an initial submission. We are part of a national network, as you know. As Carers WA we contribute to the submission being prepared by Carers Australia, but we intend to continue, as we did initially, to make a submission in our own right, from the WA perspective.

Overall we are concerned that the report doesn't provide enough attention to carers. It is our belief that whilst we can talk about services, where people are paid to provide that service, the majority of resource - emotional, health, money and otherwise - comes from unpaid family carers and friends. This is where we think that the attention in the report is significantly lacking and where we have a number of concerns.

Considering the rights of the carers in the NDIS, we are concerned about whether the carers be considered as clients of the scheme in their own right. This is an issue because it's possible that a person with a disability may not be eligible for funded services, but the carer, as I mentioned, is still carrying a significant caring load. For example, a carer with two children with moderate levels of disability will get no support. How would carers access services such as respite? Will they be assessed in the NDIS or will it be through the care support centre? What level of resources is envisaged by the Productivity Commission to be put towards this important area?

We believe that access to free carer services will need to continue. Most carers of people with disability will not have individualised funding, so they will still need to be able to continue to access carer services that are able free at the moment or for low cost. This will require, in our view, initiatives such as carer support centres to continue to be block funded. We believe it will be real challenge for staff under the NDIS, who will need to be highly skilled and have access to relevant, local and up-to-date information, both for carers, as well as those with a disability. They will need to be aware that, even where the person with a disability is not eligible for funding support, the carer may be eligible, may require support and will need to be referred appropriately.

We have already presented at the Caring for Older Australians hearing the need to share information between systems - aged care, disability, mental health, health - so as not to require the that family and carers continually have to repeat the same level of information in different systems. So we'd be looking for information-sharing protocols. But we recognise that initial access will be inevitably through the different sectors, whether it's aged care or disability, etcetera. There's a need for carers to have a clear and independent pathway to accessing carer services, regardless of the eligibility of the person with a disability to receive their own funding services.

We wonder - and would like clarification - whether the NDIA and the NIIA will be considered public service agencies. Public service care agencies are to act in ways that support carers to achieve the same rights, choices and opportunities as other Australians; that is now embedded in the Carers Act 2010. We believe that the NDIA and the NIIA should be giving a high level of interaction and that the impact and the lives of carers should come under those provisions of the act.

We are looking at the issue of paying family members to deliver care services. Obviously we define currently a carer as somebody who is unpaid. But in WA there are occasions where the Disability Services Commission has allowed co-resident family members to be paid for a limited time to deliver care services. This usually occurs for very specific cultural or geographic reasons, such as those in remote Aboriginal communities. At Carers WA we would not want to see families denied that flexibility and support, and we support the recommendation of trials rather than having one system immediately implemented that fits all. The evidence from the UK indicates there are occasions when the payment to co-resident family members has delivered positive outcomes for both the carer and the person with the disability.

We have some real concerns about whether the hazards of self-directed funding have been properly addressed. Self-directed funding can have a negative impact on existing services delivered by not-for-profit organisations. Whilst it may be self-evident to people that market forces will get the most efficient and effective services, my own experience in the UK, where they have introduced competition in certain sectors, is there's a lot of wasteful resources that goes into marketing, putting forward bids, these can be very expensive processes, and what you often end up with is that the most businesslike organisation that apparently is providing the most cost-effective service isn't necessarily providing a service of good quality.

What you find in, say, the health service in England is that the private institutions cherrypick those clients and those conditions which are easier and more cost-effective, shall I say, to manage. So we believe there's a need for pilots and trials both in different levels and types of self-directed funding and in different areas, different states, in metropolitan and in regional, rural and remote areas, and for different types of conditions, because some conditions are going to be a lot more resource-heavy to deal with than others.

I do have concerns when we talk about the existing supports for carers - carers allowances and the like - and whether that should be packaged into individualised funding. From what I know personally of carers, inevitably the mums and dads and brothers and sisters, if given a choice with money and saying, "It's either going to be given to yourself for support, for counselling or for some social support, for some information, or whatever, or it's going to be given to the person with the disability," they're going to put the person with the disability, understandably, in the forefront, and the danger is therefore that the carer themselves will put themselves second and will not take up those additional supports.

Again it may be self-evident that the resources go directly to the person who needs them, the person with the disabilities, but the consequence of that is that the resilience of those carers is going to be worn away at an even greater rate than it already is, if in a sense those supports aren't ring-fenced and given to the carer automatically. Ultimately, if the resilience of the family members reduces, then the impact and the life quality of the person with the disability is going to suffer.

So we believe that training is required for carers to support them in taking on self-directed funding, but it's something that has to be trialed, trialed extensively, different conditions, different locations, and I don't think the system of one-method-fits-all will suit, it never does in this complex society in which we live. I am now going to hand over to Nola. Nola is a carer and can talk from practical experience and from the heart. Over to you, Nola.

MS KENNEDY (CWA): Thank you. I'm Nola Kennedy. I'm 58 years old. I have five children. One of those children is 39 now, and she has got cerebral palsy. I do care for five grandchildren as well from the ages of 15 to five. My life story is that I struggled for, like, 30 years. Not having help or not knowing where to get help, your body breaks down. My child is totally dependent. She has to be toileted, showered, dressed. My children are my backbone. If I didn't have my children around to help me, I'd probably be in my grave now. I don't think carers get enough information on where they can get help and how they can get help.

My 15-year-old granddaughter is a young carer. She started caring for her auntie when she was, like, eight years old, the simple little things: putting her shoes on, brushing her hair, reading her a story. She struggled through her schooling because she sort of helped me with looking after her auntie. She has missed out on a lot. She is a young girl now that likes to get out with her friends, buy nice clothes. I feel that she has missed out on a lot. I'm really proud to say that in 2009 she was the Young Carer of the Year, which she really deserved, because she has really worked hard. I feel that carers need something for us; we're not going to stay together forever, we're going to break down slowly.

I think we suffer in silence. There's a lot of things that nobody knows that need to be told. It would take me a lifetime to tell you guys everything that I possibly could. I think we need as much help as our family members who have got disability, because we need to be whole to help them. I hope this little bit of information that I have given you shows you what my life is like. There is a lot more that I could go on about, but it has taken me about 30 years - I think Tammy was 20-something before I was built a wheelchair-accessible house, for mobilisation for Tammy.

It has taken me that long to get lots of help for her. I have just got the intensive funding that is just sort of starting to work in the last year or so, which has helped her a lot. I think I need a bit of help myself, but I don't know where to go or how to get it. As I said, we're breaking down slowly. I get $50 a week to look after my daughter. That's something that I hope you can look into, and hope for more. I hope everyone has understood my bit of information that I have shared with you. There's lots of other things that I could go into, but I'll hand it over to the next person now.

MS SCOTT: Thank you. Ms Collard?

MS COLLARD (CWA): Thank you. My name is Sandra Collard. I'm probably here with two hats: I work with People Who Care in Guildford; we run an Aboriginal HACC program and I am also the chairperson for the Aboriginal Disability Network in WA. I am here today with a little worry about the report, on reading through it, and especially concentrating very much on the Aboriginal section, and also today I'm looking more on the carers' side of things. We are looking at the issues around the type of funding that will be going out to Aboriginal families or Aboriginal people with a disability.

As Nola mentioned, she is a carer, but so is a number of others in her family. In rural and remote communities we have Aboriginal carers that are a whole community. If someone was to receive a huge amount of money for these services, how would that be distributed, when you've got 10 different people as carers for that particular client? A number of issues I thought of and discussed with some people was in Aboriginal families or for an Aboriginal person with a disability we have more than one carer. Families of a person who has a disability is often moved from home to home, so if you have got one home that is fitted with all the correct apparatus, you know, the ramps and the rails, the next home you go to doesn't have that. Are we go to follow through and keep putting ramps and rails into each home?

In terms of rural and remote, some community members with a disability are often put further back in the community where they aren't visible. Even though they're cared for, they're left more or less to fend for themselves. Also in rural and remote communities you find that the home and community care programs or the Aboriginal health services are more the carers for the clients or you have got the Aboriginal health workers and ALOs in hospitals that are constantly picking this up. There is no definition of who is out there for these clients.

The report actual states, "Australia-wide there's 19,500 Aboriginal people," and I think that was out by the time the report came in. Some of the things we'd like to see for Aboriginal people with disability is culturally-appropriate services; respite services; advocacy services - I heard the lady previously talk about the advocacy, and once again there's none there for individual people; and also for extra equipment, equipment that they need. We're talking about people with a disability and we're talking about the carers.

Today I'm here looking at how do we support the carers to look after Aboriginal people with disability. That is going to be in the very-hard basket, and we would be looking closely to working with Carers WA, to say, "How do we do it in the Aboriginal communities?" The Aboriginal Disability Network would like to also put a submission in, on how do we work with that to ensure that carers are a focal point? If we don't have the carers for our Aboriginal people that have a disability, then our Aboriginal people with a disability will be left fending for themselves or floundering in the communities.

There are a number of barriers that often put up, and Nola has mentioned those. The barriers looked at: we don't have enough information, don't have enough support agencies out there, the information isn't culturally-appropriate, and at all times, whether you're the client or the carer of the client, racism constantly raises its ugly head at the frontal service. Once we break down the barriers of getting past the racism, then we have to find out what is out there for us. So carers have a long way to go. I think the report needs to be looking at how we support the carers to support our people with a disability. Thank you.

MS SCOTT: Thanks, Sandra.

MR COATES (CWA): Just a closing comment for me. It occurs to me that we support a scheme that acknowledges both the needs of carers and the people with disability. I think the report needs a lot more about carers in there. Currently the inquiry has taken quite a functionalist look at the needs of the carers, focusing mainly on their ability to provide care, as if they're part of the paid workforce, and they don't get superannuation, they don't get paid. We'd like to see the needs of carers addressed more in terms of the needs of the individuals and their family and their ability to participate in other aspects of life, including having their own social life, remaining in paid employment, participating in education - you heard Nola give the story of her relative as a young carer. Our written submission provides more detail on this, but we hope the commissioners are able to include far more about carers in the family accommodation. Thank you.

MS SCOTT: Thank you very much. John, do you have any questions for Paul or Nola or Sandra?

MR WALSH: No, thanks Paul, Nola and Sandra. I don't have any questions, but just to state that we've heard in the hearings around the countryside and we're aware that carers are the backbone of the system. I think we're well aware that supporting carers is a fundamental requirement to get the system sustainable. We're aware that if the carers aren't supported that the system will break. So certainly thanks very much for the very clear presentation you've given and I think we hear it loud and clear.

MR COATES (CWA):   So will that awareness be translated into more recommendations for supporting carers?

MR WALSH: Well, we need to go back to the report and review it. We haven't started to draft the final report yet. So we'll discuss that with the team, Paul.

MR COATES (CWA):   Thank you.

MS SCOTT: Certainly I think it's fair to say, Paul, that just as we acknowledged with the previous presenter that people have indicated to us that they wanted a stronger focus on generic advocacy and we're concerned about that, I can say that carers groups have been well represented in our hearings but we can't really pre-empt the process because we've got to get submissions from people. You wouldn't want to think that just because we heard one person that we'd go off and change the report.

Sandra, we have had relatively little response to date on indigenous issues, even though we've got a chapter in the report. So it might be the case that I could get your card later and maybe we could have a member of the team talk to you, because it's - very keen to just check that we've got our themes right in that chapter. You mentioned the issue of the fact that people with disabilities are cared for in the community in some indigenous settings and that means that people move from home to home, and therefore thinking about home modifications for a home may not be the right way to go. So I've noted that, but have you got a solution for that, because are we talking about temporary arrangements, are we talking about things that can move with them like portable chair over the toilet? What do you suggest that happens in circumstances where people move with the carers over time?

MS COLLARD (CWA): Well, what do I suggest? I'd probably go on forever. Look, I might really just come back and explain more when I read through the report.

MS SCOTT: Yes.

MS COLLARD (CWA): I know that you've asked that particular question on how do we do that. A lot of the community people - I'll answer very quickly on that - tend to use whatever resources they have to support the person that they look after. Sometimes that is just homemade resources, you know, building their own ramps, just get a board and put it up and do things like that. Moving from home to home is also where they try and get someone in to put a rail in very quickly in a shower or in the bathroom, in the toilets; purchasing their own equipment, which is sometimes what you have to do. That's sort of the support that they have at the moment in rural and remote communities. Also I think Nola had difficulty in getting her house fitted correctly and the training for manual handling, how to use a hoist and things like that. Nola wouldn't be the only person in that situation. They're the things that we're looking at: how do we support that and how do we get around that?

One thing I did pull out when I read through the report is there is a lack of knowledge about disability rights and services for Aboriginal people. If you don't mind me just going through that?

MS SCOTT: Yes, please do.

MS COLLARD (CWA): There's limited access to services, especially in regional and remote areas. So the report talks about it but it's not identifying what's out there for them. We also notice that they don't talk about the correct or the designs of services, how does the service fit Aboriginal people? It's really trying to get a square peg in a round hole. One size does not fit all. The workforce issues is the major, major one. If you don't have the right people working with the right clients at the right time - which is Disability's own words - then, you know, it really won't work, and you need to do that. Studies have highlighted workforce issues as a responsibility of the Disability Services, but how do we work with Aboriginal people?

So just quickly, disability is a significant issue affecting Aboriginal and Torres Strait Islander people. Statistics and anecdotal evidence also suggests that a significant number of Aboriginal and Torres Strait Islander people with a disability may face a lot of other barriers in accessing the services due to a range of also complex issues, and we always like to reiterate, those issues can be historical, cultural, social, economic and geographical factors. I think that's a very important message we need to get across. The question that you did ask, how do we support that? We need to be working on those key things so that we can identify how to support it better.

MS SCOTT: Okay. Sandra, thanks for that. Well, we certainly would welcome any comments that you have on chapter 9 in particular, because I think - I could be corrected, John - you might be the first person, Sandra, that has raised that chapter with us. We have addressed the workforce issues. You may not be comfortable with what we've said. This is your chance to tell us what you think we should do. Nola, I want to come back to your story, if I may, your experience. Right around the country we've heard about people getting to the stage of burnout and so on looking after people they love for long, long periods of time. You've explained that you've been looking after Tammy for all her life. At this stage have you ever had people talk to you about planning for the future, in terms of what happens next, you know, what happens if you fall ill? Has anyone ever - - -

MS KENNEDY (CWA): No, they haven't. They haven't actually sat down and said, "Let's plan for - if you get seriously ill what's going to happen to Tammy?" We just talk between ourselves, me and my children. When I die, they take over. If I get sick, they are there. There has never been anyone that has come up to me and said, "Oh, we've got an idea. We can sit down and talk about things that we might be able to work around if these things or when these things happen." So that's another big issue, yes.

MS SCOTT: Okay, all right. Well, thank you for that. John, okay to wrap up now or have you got any - - -

MR WALSH: Thank you.

MS SCOTT: Thank you for coming along. We look forward to your submission.

MR COATES (CWA): Thank you.

MS SCOTT: I now invite CASA to come forward, please. Good morning and thank you for coming along today. For the purposes of the transcript, could you identify yourself and then would you like to make some opening remarks. We've allowed 30 minutes for your presentation and questions, so we'll just see how you go.

MS FRANKLIN (CASA): It won't take 30 minutes.

MS SCOTT: Feel free just to start off and we'll just see where we go with the conversation.

MS FRANKLIN (CASA): My name's Carol Franklin. I am co-founder of the organisation called CASA. CASA means Committed About Securing Accommodation for people with disabilities. We're a parent group and we have over 200 members. We come together because of the lack of funding for desperately needed services; accommodation is our main concern. We formed in 1999, we are a united and committed body of parents with a vision of securing permanent supported accommodation for people with disabilities and supporting their right to live independently in the community when the time is right for them and not reliant on family crisis. Our goal is to make the governments aware of the critical unmet need in accommodation, respite, therapy services for people with disabilities.

I was meant to have a parent with me today and she sent me an email last night and it's really heartbreaking:

> As it happens, we have had a crisis with Edward, who had a terrifying psychotic episode the other day and ended up in Fremantle Hospital. He spent three nights there and is now on a range of antipsychotics, antidepressants and anti-anxiety medication. According to his psychiatrist, Dr Starkstein, this is very common with autistic young men, because of the social isolation, the loss of structure after school. It's been a nightmare."

So she puts her apologies in. We put together a rough submission - I don't know if you've received it.

MS SCOTT: Yes, thank you.

MS FRANKLIN (CASA): I just want to say - and our opening statement is - the current system is underfunded, unfair, fragmented, insufficient, and gives people with disabilities little choice and no certainty to access appropriate supports. The parents of CASA thank the commission for this statement. As a group of committed parents and carers, we have been expressing these sentiments for years and until now we felt that our pleas for help and reform of the system have been falling on deaf ears. The members of CASA and thousands of other people throughout the country now feel that there's some light at the end of a very long tunnel that we've been stuck in for a very long time.

Funding the new system. It's heartening to hear that the commission has recommended a substantial increase in funding to fix this broken system. However, although the sustainability and ongoing funding is welcome and needed, the system will remain broken unless significant reforms undertaken hand-in-hand increase with funding. Any reform of the system needs to take into account evidence of aspects of the current support and service provision that are working both internationally and nationally, and not just reflect the current buzzwords many families are being trapped in. It would be devastating to people with disabilities if the funding was caught up in the federal/state grab-for-cash fight for jurisdiction. It is disappointing, to say the least, that this new funding will be used by the state and territory governments to continue business as usual. Like members of the community and the Productivity Commission, the state and territory governments need to acknowledge that the current system, including the parts that they administer, is broken.

Then we talk about person-centred care. While CASA supports person-centred care, we are concerned that any rushing to implement reforms may lose sight of the fact that a disabled person is a special member of a family; the family has usually been caring and advocating for that disabled person. In moving to centred care, the family as a whole should be included. Any analysis should include investigation of the possible savings to support family; for example, if both parents are in the workforce and primary care was provided, the parents self-esteem is maintained, they can contribute to the tax system, and to their retirement incomes, and the disabled person stays in a loving, supporting, and familiar environment. This also reduces the risk of family breakdown and their subsequent reliance on Centrelink payments.

At the moment, stress-related depression is suffered by many families currently providing primary care. Other children in the family also suffer depression and fail to either succeed or complete an education. Any new system should include safeguards that will prevent other children of the disabled person or their offspring becoming part of the growing number of young carers and, by doing that, preventing them from entering education, experiencing social interaction, and developing their self-esteem. I'm also chair of Carers WA and we run really good programs for young carers, and it's appalling to see that people as young as eight are caring for parents with mental illness.

Self-directed funding, although we support it, there needs to be safeguards put in place for the person with disability and to ensure the new system has the capacity to achieve better outcomes for the disabled person. Not all disabled people and their families have the capacity or want to be involved in the arrangements of support staff, daycare options, accommodation. In order that the disabled person or their family make these choices, they will need an extensive knowledge of the system; which services are good, et cetera. A system will need to include the capacity for supports to be altered as time and circumstances require: for example, the disabled person and their family decide to remain as a family unit for as long as possible, accessing day support; however, when the parents become older and in need of care themselves, the support that disabled person can access needs to change to potentially include residential care, again, to have safeguards in place to ensure that person with a disability continues to have a good life and one of their choosing.

I'll go on to therapies, it's one of my pet things at the moment. CASA would like to put on record the recommendation relating to access of therapies. The system as it currently stands restricts the disabled person to access therapies once the disabled person reaches the age of 18. Families have noted that the decline of the family member, as they get older and their access to therapies is restricted, often degenerates into a crisis situation, which in turn leads to a dependence on long-term accommodation, as the deterioration has impacted on the disabled person's health and wellbeing and a family's ability to support them. Access to crisis and emergency support will also need to be included in a new system. We have heard a lot about advocacy today, and our families are very strong on this.

Advocacy for the individual person with a disability and their family is going to become increasingly important if we move to a person-centred planning/funding model. A mechanism by which to develop and provide independent advice and advocacy will be needed for that disabled person and the family if they decide to purchase services. This will be needed not only to assist with the selection of the service provider but ongoing monitoring to ensure that their needs are being met and that they are getting value for their money. I am the mother of a 36-year-old boy with multiple disabilities. I am one of the lucky ones, as my son has supported accommodation, but it is not what I would have wanted for him.

MS SCOTT: Carol, are you able to talk a little bit more about the therapies that you'd like to see extended beyond 18, the cut-off point when a person hits 18?

MS FRANKLIN (CASA): What happens is you have early intervention, you have school-aged therapies, and it seems as though your child is fixed when they get to the end of school. My son has a very rare syndrome. He is in a wheelchair. He has degenerated so much that he is doing less and less for himself. He has sat in a wheelchair for most of the time without therapies to stretch his legs, so his legs are now bent at a certain angle; even in bed you can't straighten them out. If we had had ongoing therapies, he would have still been able to take some weight himself.

Stephen has moved into a group home, and with regard to speech therapy - I'm not knocking the staff, they are paid very poor money - they are terrific people but they don't have the knowledge recommended to work with these guys. Stephen is nonverbal, so he uses Makaton and none of the staff at the house know Makaton so he gets frustrated. He has now been labelled as having bad behaviour, but it's out of frustration because nobody understands him. So it would be wonderful to have the therapies in the group home. Stephen is in a house with four other people, all of them are nonverbal. To me, it's imperative that the staff can communicate with them.

MS SCOTT: Yes. John, do you have any questions for Carol?

MR WALSH: It's very difficult not being able to see you, Carol. I can sense your feeling and how strongly you're presenting on this. We have heard a lot about the carer support networks and the local area coordination in Western Australia. Could you comment a bit about what more might be done in the way in which families and carers are supported beyond those facilities?

MS FRANKLIN (CASA): I think all stems back to actually working with the family, and not the family being told what is there. Families have a great knowledge of their person that they are looking after, but on the whole it's ignored. You know, I have always said over the years, "My son has a disability, I don't," because I've felt that everybody has sort of put me down, from the medical profession down. I don't know what else can be done, except for actually sitting down and working with families, for it to be understood that they know their person and they're the best ones, with the knowledge, to look after that person. I don't know if that helps.

MR WALSH: It does, and it comes through in your submission from last year. I think you mentioned a life-plan approach that supports changing as the person's needs change, and the particular one about people with many kinds of disabilities still needing to learn after the formal school system has finished is a message that comes through fairly strong.

MS FRANKLIN (CASA): I have been a strong advocate for school not finishing at 18 for people with disabilities. I would like to see it possibly go on to age 25. I mean, my other children went to university, so they were still at school till they were 25. My son didn't have that option. When he was coming up to 18 he was just beginning to learn, and suddenly that all stopped, and he couldn't get a job. He is quite happy. He goes out and does bowling and art and things, and he quite enjoys himself. But I think there is a need to continue education. Even if you use that time between the age of 18 and 25 to transition them from school to day placement or employment, so that there isn't that stress on the families and that suddenly at 18 you become an adult and there's nothing there for you.

MS SCOTT: The idea that needs change over time is, hopefully, reflected well in the report. But if it's not, we need to look at that. Carol, it seems like you have got multiple hats, multiple associations with which you're very involved, and of course your caring responsibilities with your son, and you might not have had a chance to look at the detail of the report.

MS FRANKLIN: I looked at the short version.

MS SCOTT: The overview. Fair enough. There's a lot to read, so please don't take it that I'm assuming that you have read it or that I think you should have read it; I think you are, quite reasonably, a very busy person, and this takes a lot of time to get on top of. But if you had a chance to look at page 526 in the big report, just that page, I'd very much welcome your input on it. We suggest on that page that there needs to be contact with the family before the assessment process proceeds, that there needs to be an understanding of the setting of the individual with disabilities - you know, that there might need to be a really quite separate assessment, the situation of the carers. I keep writing down "carers", but I think I should be writing down "family", because you have made the good point today about the importance of siblings, which we have heard before, but I don't think it quite had registered with me till you said it.

MS FRANKLIN (CASA): There's three years difference between my two boys. When my eldest son was four he said to me one day, "Mummy, can I be disabled?" I said, "Why?" He said, "Because everybody comes in and they love Stephen, and they don't love me." It really opened my eyes to the fact that the family had to be included. So I sat down with all the therapists and said, "Right, you include Darren into the system," and it was really good. So when my daughter came along, she was just included.

I always say that I have a good child and a bad child. My eldest couldn't wait to get out of home; as soon as he was old enough he went. I don't mean that in a bad way, he has always been in work and he has done a terrific job. He didn't come back to us really until Stephen got accommodation. I think the pressure of him thinking that he might have to take over the reins if anything happened to us was too much for him.

My daughter, who is eight years younger than Steve, has grown up with him, and she idolises him, but to her detriment - she is 30 now and she is a pharmacist, a brilliant career, but a homebody - she won't go out and socialise, she lives her life for Stephen. So it really affects children in different ways. I have just had a terrible three months. I have had three families tell me that one of the siblings have committed suicide through the pressures. It's something that isn't acknowledged a lot, that the siblings do have problems.

MS SCOTT: Well, you're opening my eyes to this. I had heard earlier things, but your testimony today is very powerful on that point. So thank you for that. One last area I wouldn't mind exploring with you. You have expressed concern about individualised packages and people having choice. Maybe we need to be clearer about this. That's the advantage of hearing from people, because one can go back and read it again and just say, "What were we trying to say, and why are people concerned? Do we need to change it?"

The experience overseas is that a lot of people do not want to be the manager of their funds and their families don't want to be the manager of the funds, because they're very busy people. But they like the idea of choice, so they can say, for instance, "That particular service provider is great. I don't want to have that one. I don't want to have that person in my home," or, "I don't want to have home respite, I want to have a genuine two weeks off, a break for the person with disability and a break for the family." They want to have choice.

You have expressed concern about self-directed funding, and the last group expressed concern about self-directed funding. So I'd like to have a better understanding. If you had the option that you can nominate the services you want, and we'll arrange it for you, you can nominate a person to do the arranging for you, because you trust them, that they have been a good service provider in the past and now they're going to act as the broker for you, or you love a challenge in your life and you want to have total control over the package, if we set it out like that, made that absolutely clear, that you could always just simply say, "Perth Home Care Services, that's who I want to go with," and they'll arrange the rest, would that satisfy you, or are you still very concerned that that's not going to suit families that you're in contact with, and your own circumstances?

MS FRANKLIN (CASA):   A lot of members of CASA are - what I call "at the high end of town" - really high-support-needs people. So I can't really talk for the ones with the lower stress levels, if I can put it that way. When you have had a person with disabilities in your life, the stress levels in that house are horrendous at times. They're also lovely at times also; don't get me wrong, I love my son, he is beautiful. I am concerned that we are just adding another stress to some families, who feel that they should take this on, you know, because - and this is again the buzz words, the "in control" and the like.

It's just a gut feeling I have, from working with lots of families that are under lots of stress, that it would put another stress on to them. I mean, I would say that 90 per cent of our families would go for the first option, say, "This is the agency I want." I am also concerned for that person with a disability, for the milder disabilities; you know, is it what their parents want or is it what they want. Quite often it differs. A lot of parents - I mean, I was one of them - cocoon their child and say the disabled person can't do certain things. Are we going to restrict them in that way? It sounds really awful, but I have seen it lots of times. That's why mentioned the importance of safeguards.

MS SCOTT: That's very helpful. We will have a look at our text around assessment. If there is any chance you could just have a look at that page for me, that would be fantastic. John, any further questions for Carol?

MR WALSH: No. Thanks very much, Carol.

MS SCOTT: Thank you very much for coming along today. Everyone, it turns out we're going to have a break now. We will come back at 11 o'clock with Brian. So we now have a break till 11 o'clock, John.

MS SCOTT: Ladies and gentlemen, thank you for attending today and I note that there are some new faces in the audience, so welcome to our public hearing. We're going to shortly hear from Brian. But just to explain the situation, we've got Associate Commissioner John Walsh on Skype and on telephone. So if it turns out the Skype falls out, please don't think you're losing contact; he's listening very attentively. I have to say, the system hasn't worked well today, John, and I apologise to the audience that they can't see you always this morning. For some reason it has been particularly unreliable and we're not too sure why; it's been working very well in our other days of hearings. Anyway, hopefully it will work well now.

Okay, Brian, thank you for coming along today and thank you for providing us with some material in advance of your presentation. We've allocated 20 minutes to your presentation, but you may wish to allow a bit of time for John and I to ask you a few questions. So without further ado, I understand you're representing yourself; you're not representing an organisation. Is that correct?

MR O'HART: That's correct.

MS SCOTT: Please commence your presentation.

MR O'HART: In my notes to you I indicated there were eight sections I would like to focus on. First of all, the terms of reference: the options for private contributions, including co-payments, fees, or contributions to enhance services; secondly, assessment of the disabled and their carers, jointly; the assessment tools for the toolkit; the assessors and case managers; the transition points and early intervention; the trial period; the plethora of agencies; and a few other minor considerations, and on the base of my submission I put the brief analysis of the five options that were presented in volume 2, mainly for my own reference and to see the difficulties inherent for state governments and ministers in coming to some conclusion or solution through that maze.

In the terms of reference, one of the terms was: option for private contributions, including co-payments, fees and services to enhance services; that was item 7 in the terms of reference. I've drawn on the following extracts from volumes 1 and 2 and, it is stipulated there, the role of co-payments is a vexed one - which I totally agree with - there should be a capacity for a person to add their private funds to a funding proposal, and the commission considers the role of the Special Disability Trusts should be reviewed once the NDIS is up and running.

I've taken those three on board and my comment is: I am of the opinion that the SDTs should be an integral part of the NDIS framework from the outset. The restrictions on the conditions embodied with the Special Disability Trust legislation of 2006 should be relaxed and used as a mechanism to enhance NDIS. The track record and restrictive natures of special disability trusts is clearly evident in the statistics of the uptake. On 13 October 2005 the then prime minister John Howard announced the initiative to introduce special disability trusts at a projected cost of $200 million. On 20 September 2006 legislation was enacted for special disability trusts. FaHCSIA modelling indicated there would be approximately 5000 SDTs in five years. Within four years there were only 33 Special Disability Trusts established at an estimated cost of 6.96 million.

The data that I secured through various ministers - and they got back to me and I collated the information and responded back to them - was that, up until then, 5.7 million had been expended and 82 per cent was absorbed in bureaucratic management; no-one will deny that figure. An interesting side aspect to the special disability trusts was that in December 2005 I was contacted by Noreen Fynn of Carers WA, to see if she could put my name down to be a representative on the advisory committee on 11 January, when I had a commitment to take my daughter to hospital on the 16th for a week. I had to ring her to see if I was going to be called up for whatever reason and just as I phoned her on that day she had an email to say that there was only one person from all agencies in Australia that had been nominated to serve on that committee. I think that's tragic, and you're looking at that person.

Getting back to the SDTs, hopefully such an inclusion would provide incentive to parents to commence saving when their child is first identified as having a severe disability at birth or at a very young age, to supplement the NDIS funds when funds allocated prove inadequate, particularly when assessment is in dispute and complaint or reassessment is taking place. The report states that the scheme should provide reasonable needs. This will not always be the case and assessors will not always be accurate in their assessment analysis. This fact is recognised in the report where it is stated in cases exceeding the norm; this may be the case where, say, an individual with complex needs disagrees with an initial assessment outcome. I don't want to reflect too much, but I'd say our situation is a classic.

The assessment of the disabled and their carers. The most critical fact in any proposed NDIS is the accurate assessment of the disabled person and, in many instances, the assessment of the carers. In particular, the case of ageing carers with medical problems is so relevant. The draft report clearly reflects this concern and is applauded for this recognition. The following extract from the draft clearly illustrates this awareness and I wish to reinforce this, "Assessments should be person-centred, taking account of the person's unique circumstances." Out there they are unique: you can't take one Down syndrome child and say, "That fits all"; they are all different. It depends on a lot of factors: their genetic background, their environment, and so forth. It would not be reasonable to expect elderly carers to provide the bulk of support, but it would be appropriate in those instances to expect parents of a young child to provide overnight support for a reasonable period during the week, as this is what all parents do. I think this is a very important point and should be absolutely highlighted. It says here, "This is aptly stated in the draft overview; it would not be reasonable to expect an 85 year old to provide the bulk of her son's disability care."

In previous reports to the Senate Standing Committee, tabling such reports such as Who Cares and Shut Out, this aspect has been stressed over and over and over again, even in parliament; Bill Shorten stated in the House of Representatives on 23 June that:

> We are aware of the enormous burden carried by families and carers in this country and how heavily our social obligation to care for people with disability falls upon this dedicated group. Carers, particularly those who look after an adult child with a disability, are often described as saints or with the phrase, "I don't know how they do it."

And these are his words -

> I would like to suggest they are not saints -

and I agree -

> they are just ordinary people doing an amazing job out of DNA hard-wired love and out of the knowledge that if they do not do it, it will not be done.

Unfortunately, there comes a time in ageing carers' lives when they are so medically and physically disabled and exhausted after caring for a disabled offspring for four decades or more that they cannot continue to provide support, even if they are endowed with all the love in the world.

In the case of the rider, I recently stated in correspondence to the premier of Western Australia, the minister for disabilities and the director-general for Disabilities Services Commission that my wife and I are of the opinion that once carers have reached 63 to 64 years of age the stresses, strains and pressures of coping with a moderate to severely disabled son or daughter increase exponentially each year after that. That is our experience. There has been quite a bit of interplay between myself and the ministers and Disability Services Commission over the last 18 months, but I won't go into that.

Both myself, as a 72-year-old father, and my wife, at 69 years of age, have numerous serious health issues. We find it very stressful and distressing in our endeavours to cope with the very modest funding currently in receipt from DSC. Under the previous CSTDA in June 2007 the preceding Commonwealth government made a commitment of $962 million over five years to provide a comprehensive package for older carers. Many older carers within the community are asking, "To where has the money gone or been diverted?" One senior politician who was in the previous ministry just basically told me it has gone into a black hole.

As a side issue, after round 26 or 27 of the local funding here in WA I did an examination of the funding and statistics proved to me that at that time all the applicants over 65 years of age could have been funded out of the balance of the money that was in kitty and that there would have been a surplus of about $1.3 million. By the time it got to the round, things had changed. That was my analysis, and DSC and the minister has that. There are five or six assessment tools listed in the toolkit. I have been trying to find out about a few of them and have contacted people in the eastern states. Having very little knowledge of these assessment tools, I am in no position to offer an opinion.

However, I am certain that there is sufficient professional expertise to construct assessment tools to provide a range of tools to adequately deliver reasonable and accurate outcomes. The commission has identified the need to have a range of tools to address the priority needs of the disabled individuals, and I think that is very, very important - for instance, complex cases and episodic difficulties encountered in the assessment - and I concur with the statement that an assessment tool must provide a reasonably close estimate of a person's support needs and resource allocation to achieve. That's why I come back to the special disability trust, to enhance if they're not adequate. People's allocation needs will vary in their allocation needs.

Of significance is the recognition by the commission that all carers receive their own assessment. It is of paramount importance that the aim should be to support the relationship as well as the carer when you have ageing carers and ageing disabled people. The statement within the report says that in a system as large as the NDIS there would be greater scope and grounds for specialisation, and I totally agree with that. I totally agree that tools should be open source rather than privately copyrighted. "Where tools are in the public domain, it facilitates transparency and further research and development," and I couldn't agree more with that.

It has been my experience in Western Australia over the last 12 months that my endeavours to secure knowledge from the Disabilities Services Commission of the risk factors and the use of an electronic tool upon which the combined application funds are allocated have proved fruitless. In this state's June 2007 auditor-general's report, Performance Examination, A Helping Hand home based services in Western Australian in relation to the above-stated concern it states on these aspects, "Cumulatively, these factors Cumulatively, these factors give the assessment process an air of secrecy that is out of step with public administration," and I could not agree more, and this is one of the reasons why I would not serve on such a panel as it is now structured.

The above practice is at variance stated as the objective of the commission.

People with disabilities and their carers will be looking for information and guidance about assessment procedures, case management, self-funding and the complaints mechanism. That should be open, and, if it ever becomes a reality, I think that is terrific. On the next item, assessors case management, the competency and the professionalism of assessors will no doubt be central to the success of the NDIS if it becomes a reality. Statements within the draft report are indicative of this fact, such statements as below: assessors should be drawn from an approved pool of allied health professionals, GPs and others, reporting through the medical system, contact general practitioners and allied health professionals - volume 1; and a similar extract I've got there.

Reference is also made to two significant factors in the assessment process, assessor training requirements, the training of professional assessors, and careful calibration and gate-keeping and a hierarchical professional approach at the micro level where they become episodic and complex. You have to have top people there, and they can be drawn from top medical specialists with experience in handling all cases. Comment, it is the opinion of the writer that the knowledge of top experienced medical specialists with the wide-ranging spectrum of disability should be utilised in training and developing competency.

With regard to case managers, the report states that the model of local area coordinator as used in Western Australia may be the best form of case management; that is on page 360 of volume 1. All I can say is that I would appreciate information on which this opinion was formed. Relating to cost of local area coordinators - and I am not putting them down, they have a role - it states in the WA state budget 2010 papers that 241 full-time equivalent local area coordinators are employed at a projected costs of $24,049,000. I foresee under an NDIS with competent assessors information readily-available, an adequate complaints mechanism in place and central regional administration that substantial costs could be saved in this area.

As I pointed out to Ken Baker recently, an ideal place to have the trial for the 10,000 would be here in WA, because you've got the tyranny of distance; you have got the indigenous population; you have got people spread out all over the place; and you have got regional centres, and, if you have regional centres, they have got to be staffed. I just make that comment on the trial period off the cuff there. I have also put the rider here that the scheme would commence in a particular region in Australia, providing high quality service to many thousands of people. This regional arrangement would incorporate all the functions and the structures of the NDIS.

From my perspective, having some financial knowledge, the key actuarial information needed to underpin the scheme management is so vital in this trial period. There's five options being made available. The commission has the last option. If the politicians and the ministers and the argy-bargy between governments takes place and they offer one of the other five or a hybrid, in the actuarial diagnosis if they're going to take away carer allowance, carer payments, if they're going to increase the GST by 10 per cent there's a whole shaft that they have there that they can look at to do.

If in the trial period all of those factors should come into play to get an accurate assessment form the actuaries when they diagnose, not just putting numbers as ether up in the clouds. Comment was also made about replacing the existing plethora of agencies, on page 313 of volume 1. Unfortunately, I concur with this fact. As a member of six such agencies, I often wonder what role or contribution they make that benefits the disabled. More often than not, they no more than conduits with the same information.

Often I receive an email notification from them all in relation to the same seminars, workshops, et cetera. Furthermore, it's quite common to receive follow-up reminders. In all, I can be advised of such events as many as 15 times. These agencies are primarily funded by state and Commonwealth governments. I am of the opinion that they are unproductive and wasteful of funds - in respect to this, I mean right across the board. Such funding would be better directed to the immediate needs of the disabled. An NDIS would be beneficial in this regard.

MS SCOTT: Brian, I think you might have missed your earlier points on transition points and early interventions.

MR O'HART: That's paramount. Yes, to me, it's vital. With regard to transition points and early intervention, we can see transit patterns coming through here, and I think this is very important to take on board. The draft report listed six transition points. I would like a seventh listed and raised in priority to the top of the list: at the point where carers reach the age of 63 to 65 years of age and have care for a moderate to severely disabled son or daughter for in excess of 40 years. Early intervention is important where it can be demonstrated that it meets with success.

I am in total agreement with the statement regarding systemised reviews of rampantly-controlled trials being at the top and representing the strongest evidence; that was in volume 2 at page 58. This was clearly expressed in submissions 371 and submission 54, and one was provided by the previous speaker. It is obvious the commission is very conscious of this aspect as it has stated its concern in many other sections of the report. Currently a trend is emerging and an industry is rapidly developing in respect to early intervention.

An expectation will emerge and current participants and their parents will expect considerable support in the future. When you look at the stats that they're looking at, 80,000, and about 350 of the others, and you look at the distribution of the last 18 months right across Australia, particularly the east coast, in autism and other areas, it starts to make you wonder, these people - the current allowances that they have, their expectations and the whole system - in the years to come will be very politically active, make no bones about that, because once you give something to someone and then take it away, you've got a problem.

A minor consideration is it is pleasing to note board members from a variety of locations in the report, not just Sydney and Melbourne. That was pointed out. I would also like to see updates on progress after state ministers meet, so that politically they can let the public know what is in train, how they think, that should be another form of information. I have listed the tax options there, and whatever comes out of that, I don't know, but the commission's is the fifth option and the tax swap.

As I was speaking to you earlier about, I am concerned at some of the trends in the last eight years in WA. It has been obvious that when people go to the media the get a response. The lady who spoke before me, when she went to the media she got a response. Another close friend of mine with a severely disabled person when he went to the media he got a response. At the last hearing a woman, two people before me, stated her case - they're on the transcript - where she was getting $33,000 in funding and she explained why. A very sad case.

Since then she has targeted 102 MPs here in WA, they have taken her case on board. She has gone to the Australian newspaper - I think it was about 26 February the article was in the paper, she spelt it out. In the transcript she said it would cost $150,000 for her and her husband to care for a child above the $33,000. She has got a very marked increase in funding under that process. I will not divulge more, due to confidentiality, but she secured her goal, and that is what I am very concerned about.

MS SCOTT: Brian, thank you very much for putting together that very thoughtful presentation. John, I have got a few questions; but I'll let you got first, if you like.

MR WALSH: No. Brian, thank you for that. That was a very helpful presentation. The thing that came through for me strongest of all was the issue around the need for accountability, transparency, governance and efficiency in the system. I think the use of the word "secrecy" in fact in the auditor general's report about the assessment process is something that hopefully we can address in the NDIS report. I think governance and productive use of funds is something that the Productivity Commission's report is trying to achieve very strongly, and I appreciate your submission.

MR O'HART: I would like to just raise one other point. In one of the options they talk about inefficient taxes. Wouldn't that rile up the state ministers and state governments, "inefficient taxes"?

MR WALSH: I'll leave that one to you, Patricia.

MS SCOTT: Thank you. Occasionally the economist gets a bit of attention shown to them. All right. Well, Brian, I can see that you've read the report very carefully, but for transcript purposes, for the other people that will read this, we do rely on the analysis undertaken by the Henry Tax Review, in terms of categorising and doing measured assessment of the efficiency loss from taxes. There is always an efficiency loss with any tax; because, if I'm taxed a dollar, I could have used that dollar for some other purpose.

You get efficiency losses because of distortions created by the cost of actually collecting the tax, and so on. It might well be the case, Brian, that we rile a few people, because they might be used to a system that they have created, a political system. The fact is we think that people are after certainty. I guess that's a question I was going to ask you. In here you've stressed the need for us to think about another transition point, that there needs to be attention paid to people who have had caring responsibilities for a very long time. We did have that as a high priority group for the initial rollout of the scheme. But I think your idea that we make it more explicit in the report is very well worth considering. Can I just turn to your own circumstances. If you don't want to talk about it that's fine, but do you have any certainty about the arrangements now for your daughter, given that your health is not good at the moment and your wife's - - -

MR O'HART: No. This is a funny thing. I usually come to these shows and never talk about our problems. But, no, our daughter is - at birth, she is now approaching 45 - cerebral palsy; epilepsy; eyesight problems, basically can only see out of one eye; hearing problems; malformed limbs; hippocampus was damaged at birth. The hippocampus is the processor of the brain. Other parts of the brain were affected. Sometimes when she was a young child, three years of age, we used to have to wait up to six hours for a response; because where you often thought she'd been naughty or disobedient, and I could see in my experience that - because there's no emotion coming with it, I knew there was something wrong. Her twin brother is one of the most gifted people to walk this earth. Lisa has had ability, huge ability, but we'd wait six hours for a response and then the logic and the rationale behind the response was incredible.

Now, with all eight medications, getting psychiatric help at the moment, a new drug - you know, I have nothing but compliments to pay for the medical staff and the support. Perth Home Care Services that render service to me are absolutely excellent in a most difficult, complex field. I see Perth Home Care will be here later on this afternoon. Everyone has thrown the best they've got at her, but as I said the time is coming. She has all the problems in the world and her fighting spirit - we could see the stress and strain she is under. She could crack at any moment.

MS SCOTT: You are in receipt of a package from Disability Services

Commission?

MR O'HART: Yes.

MS SCOTT: Does that have a forward element to it? Do you know what package you will receive in the future or what Lisa will receive?

MR O'HART: No, we have an application and it has gone in to the second round, the next round. So I don't know what will happen there.

MS SCOTT: If you dropped dead tomorrow what is likely to happen to Lisa?

MR O'HART: Good question. In the lap of the gods. Possibly - heavens above, I'll send an email to DSS and say, "You've got a problem." That has gone through my mind many a time, to just say, "Right, we've coped for 45 years." We have seen what has happened in other cases less fortunate. I've seen some bad cases because I've been connected with disabilities for 35 years. As I was telling you earlier I've had some remarkable achievements in the last 10 years getting land tax exemption and water rates and council concessions for carers, for parents in our situation.

I was instrumental in 2007, through a very senior cabinet minister, of getting the thresholds for the pension for a married couple lifted from about 525,000 to about 830,000, because through PWDWA I was getting people directed to me, grandparents and parents, who have severely disabled offspring who had bought an apartment, 150, 160 thousand, and of course they were losing their pension or part-pension, losing the benefits that came with it. They couldn't say anything to their grandchild. They couldn't say anything to their son or daughter. They had to bear the brunt and the cost of it and I go back to a CASA meeting that Ms Franklin was at.

MS SCOTT: Yes, Carol.

MR O'HART: One of the senior politicians who saw our situation said to me, "Brian, this is apolitical." I said, "Yes." He said, "Get onto Simon Crean," and I did the next day. Annette Ellis phoned me that night and since then we've worked on this. In 2007 we had the thresholds for a married couple lifted by 56 per cent, basically through Costello and Howard. I was amazed looking at Q and A recently Turnbull said Howard had a soft spot for people with disabilities. Well, believe it or not, the evidence is there. Then we designed a brochure, because I told them that they could cross-reference all the pensioners that had disabled people whose entitlements were being cut through by this - cross-referenced on the database. They sent out a brochure. I helped compile a brochure. It was headed, "Aged pension, disability support pension carer's allowance," so it was to capture that market. It was sent out to everyone in Australia. Even I got one, so I've got a souvenir. Also in the process rather than losing $1 for every $2 as your asset increased, to stop the erosion we had it changed from $1 to $3, because of the capital appreciation of property. That was, behind the scenes, something that has helped people.

MS SCOTT: Yes, that's a real achievement. Brian, can I go back? How does it leave the rest of the people in caring responsibilities when you don't know what accounts for why somebody gets one package and another person gets another package? What does that do to the confidence of people?

MR O'HART: Well, most, I'd say 99 per cent, don't talk about it. They're so busy caring. I know a classic case in Manjimup, my home town. A mother there, 73 years of age, with a 50-year-old who needs all the assistance in the world, but she can only get respite for about four hours a week. It's sad. There's sad cases all around, but they don't surface. People have said to me, "How do you do it?" Well, I said, "Someone has got to get out of the gutter and do it." I was at a top conference years ago, I think Michael Kendrick was there - emailing Michael Kendrick, one of the foremost radical provocateurs in the world on people with disabilities coming out to South Australia shortly. They said, "How do you do it?" I said, "Well, I have a strategy. I fight for a month and retreat for a fortnight, but they know I'm coming back," and that's what it's all about.

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

MR WALSH: No, thank you, Brian.

MS SCOTT: Thank you very much for your time today and again, for your very thoughtful submission.

MR O'HART: Thanks very much.

MS SCOTT: The Ethnic Disability Advocacy Centre, thank you.

MS YEONG (EDAC): Good morning, and thank you for the opportunity to speak to you directly, first of all, to the two commissioners. My name is Jenny Au Yeong, I am the CEO of the Ethnic Disability Advocacy Centre. The Ethnic Disability Advocacy Centre is an independent advocacy agency representing the rights and interests of people with disabilities from culturally and linguistically diverse backgrounds. We have previously provided a fairly comprehensive report to the initial consultation. We love the opportunity, we thank you for the opportunity to comment on the draft report. I'd also like to introduce my co-presenters: Dr Karen Soldatic, representing the EDAC board, and Arelene Gregory, of systemic advocacy. So we'll be sharing the presentation this morning.

Firstly, I would like to congratulate the Productivity Commission in producing such an extensive report. I'm still going through the 800 pages; there is just so much there to absorb. Structurally I think it seems quite sound to us, but I think in bits it is very thin in implementation and operation procedures, and what we would like to do this morning is to pick a couple of issues from the report to comment on. Later down the track, before your expiry date, we would be providing a rather comprehensive written report, so thanks for the opportunity again. We will probably pick about four or five topics this morning for discussion, and we hope to have a discussion and for you to be able to question as well.

MS SCOTT: Thank you.

MS YEONG (EDAC): Can I firstly introduce Karen and get her to start.

DR SOLDATIC (EDAC): Thank you for the opportunity to provide feedback today into the Productivity Commission's NDIS proposal. The main areas that I will be talking about today are the issue of what is meaningful choice; the competency of private providers; the issues of protection and safeguarding for the rights of people with disabilities through independent and systemic advocacy; and the overarching governments' framework, both of the NDIS but also within disability services and supports themselves.

We feel that the report offers some extensive benefits for people with disabilities, like more money for services, individual funding, attention to Aboriginal people and greater stability of funding overall. However, one of our concerns is the underlying market based ideological commitment within the report itself and the way that this may or possibly impede issues of social inclusion for disabled people and particularly disabled people from CALD communities. At this stage we feel that the market ideological framework does not recognise the unique level of vulnerabilities for people with disabilities. These vulnerabilities are particularly heightened for people from CALD communities due to the multiple disadvantages they face due to the intersectionality of disability, race, and ethnicity. A recent Australian example of this is the Office of the Public Advocate report in Victoria which actually reveals the high levels of abuse and exploitation that many people with disabilities face, both in informal and formal care arrangements.

Such reminders should be central to any conceptualisation and design principles of a national state-funded disability support scheme. The underlying commitment to the market which underpins the proposal erroneously assumes that people with disabilities are able to vote with their feet and move to another service if they are unable to have their needs met or have found the service to be exploitative or abusive. The report's emphasis on the marketisation of services to promote ideas of choice assumes that people with disabilities are highly mobile consumers of care markets and can easily move through the care and support supermarket with few impediments, but we know internationally that there's a substantial body of research that contests these basic assumptions of care consumers and that, in particular, care markets themselves do not openly provide information and that people with disabilities, given their position of poverty because of their heavy reliance within the welfare system, that they are unable to access a range of information that can actually inform their real choices about what their services provide. Also, too, people with disabilities are increasingly faced with the option of having to sacrifice care quality for care hours. These kinds of issues, based on the idea of choice, are not actually fleshed out within the report itself. The positioning of choice further assumes a level of in-depth knowledge about the available choices within the care and support market.

Secondly, we are aware from the international emerging research into the quasi market and full market implementation of care markets that actually this results in a diminishing number of choices within the supermarket of the care market, particularly as non-profit providers are actually generally bought out or services taken over by private providers. So actually choice at the real level, at the local level, becomes diminished rather than expanded. This raises our concerns around private providers, especially as globally we know that, increasingly, providers who are engaged in services of exclusion and segregation, such as detention centres and also prisons, are increasingly engaged in providing aged care and disability support services internationally. Therefore, we have concerns about how these kind of values of exclusion and segregation can be brought in to promote participation and inclusion.

This leads to our final point, around the governance structure both of the NDIS and of services themselves. The idea of self-directed supports really emerges from the disability rights movement struggle to democratise services, so that services are actually governed and administered by people with disabilities rather than for people with disabilities; that is, that people with disabilities want to have more than mere market choice, but actually want to be part of the decision making process that constructs what these services will provide. They actually want to be involved in deciding what those choices will or should be, not actually choose from a range of choices.

Therefore, we actually want to see, first of all, the NDIS, the overall governing structure, far more integrated, particularly around the advisory board and the overall governing financial board. We'd like to see not just a closer relationship between the two, but also that an affirmative action policy is implemented to ensure that people with disabilities, the end users of services, are actively engaged in this process and that this is representative of the broader disability community that covers issues of ethnicity and race, such as the indigenous community and people from CALD backgrounds. We'd also like to ensure that service providers, whether they're non-profit, public, or private, are regulated in a way to ensure that there is greater end-user involvement throughout the organisational structure: otherwise, services themselves, how can they change; what is the feedback loop to ensure that end users are collectively providing feedback to ensure that structural organisational issues are actively responded to.

We feel that these issues are particularly pertinent, especially around the role of advocacy, and currently we are a little bit disappointed that there is no realisation of these vulnerabilities that face people with disabilities and that advocacy services aren't actually acknowledged as an independent service from the other aspects within the care market. Therefore, we feel that it's important to ensure that the voices of end users are heard throughout the system, from the top layers of the system down to the ground level. We feel that the report hasn't paid enough attention to this and, therefore, ultimately provides a limited understanding of the relationship between disability, citizenship, rights, and the role of disability care and support in the realisation of this role of citizenship. Thank you.

MS SCOTT: Thank you.

MS GREGORY (EDAC): Hi, thank you very much for the opportunity to provide feedback today. Today I'll be talking about the vulnerability and disadvantages of CALD people with disabilities, because of their language and cultural situations. CALD is often used to describe the complex multicultural nature of Australian society. CALD communities are not homogenous, but consist of micro-communities with disparate practices and beliefs. They include independent migrants, refugees, and humanitarian entrants, with the latter frequently drawn from areas of serious conflict and facing a greater risk of obtaining other illnesses like mental illnesses, for example. Many migrants and refugees are valued contributors to the Australian society who work hard, volunteer within the community and pay taxes but are frequently excluded from basic services and support for family members who are elderly or have a disability or mental illnesses.

People from CALD backgrounds with a disability are prone to triple discrimination, such as their ethnicity in mainstream society, their disability in mainstream society and their disability within their own cultural community due to cultural perceptions of disability. We felt that there was a minimal mention of CALD people from non-English speaking backgrounds in the language of the report. It only mentions, and I quote:

> The provision of information and referral services should take account of cultural and lingual diversity -

without a mention of the benchmark strategies and measures as to how this will be achieved.

Our recommendations from EDAC are as follows: that NDIS-appointed assessors from assessment to service provision must be culturally responsive and competent to the needs of citizens from CALD backgrounds; that NDIS should have sufficient safeguards and supports in place, such as the right to have a qualified interpreter present during assessment, when receiving service supports at any other process as well; consumer training is paramount; fourthly, to ensure that people with disabilities that are vulnerable are not exploited and concerns around how the system will be phased in and taught to the whole community, including people with disabilities from CALD or indigenous backgrounds.

We are also concerned about the system in relation to the complexities of family relationships, the caring role and the interrelationships between family members. The fifth point is language interpreting service and funds should be a separate allocation and not be included in the budget allocation or entitlement. It is an equity issue. Language should not be a discrimination. It would be unfair for people to use their NDIS lump sum payment to access the same supports that mainstream Australians have access to based on their language understanding. The sixth point is that support needs must be reasonable and necessary to CALD-specific citizens in benchmarking criteria. For example, if a service requires a longer contact time frame due to the use of interpreters the benchmark for this person must be higher. Thank you.

MS SCOTT: Thank you very much. John, would you like to lead off?

MR WALSH: Yes, I'll kick off. I'd like to talk a little about what you regard as the best resource allocation methodology. We've heard a lot about problems with block funding, giving large amounts of money to providers with providers effectively having control over how that money is disbursed. You've raised a lot of issues involving being given to people with disability, on the basis that they don't have, at this stage, the capacity to make decisions. So a competitive market might effectively have the same impact in that large providers will become very powerful, in effect.

So could you give us some advice on what you see is the way to overcome this dilemma?

DR SOLDATIC (EDAC): One of the things that we're actually looking for is some type of regulatory framework that ensures that services who provide or who are able to gain access to funds through this program - either through individuals actually going to them to purchase or through the model where they are given the service - that there is an overarching governance framework that includes people with disabilities. So, for example, as an advocacy agency within our constitution we have a 50 per cent representation required within our constitutional framework to have end users or our members actually on the board. The management structure within the organisation actually have a range of affirmative action policies that promote the employment of people with disabilities or who are likely to be end users throughout the organisation, particularly in the hierarchical decision-making process within the organisation.

Other kind of feedback loops include such as providing end user committees where end users can come together so they can actually work out, "Okay, well, what is my personal issue in receiving this level of care, but what might be the issue of the overall service?" So there are a range of reference groups and committees within the service that comprise end users themselves, and therefore this can feedback into the organisation. The other issue is, I guess, that also ensuring that people with disabilities can actually become care workers. So some people with disabilities might only require certain supports but they might also be able to be employed as care and support workers within these services. So it's really about embedding the end user throughout the organisation and ensuring that there's a regulatory framework to enable this to occur. Otherwise all we're going to end up with services doing exactly the same.

MS YEONG (EDAC): I think we believe that the regulation should also extend to service providers. We envisage there will be a fair bit of competition when this comes rolling. The service provisions need to be regulated to ensure competency in providing services.

MR WALSH: Just your view on whether - over-regulation, which I must say we hear a lot about over-regulation.

DR SOLDATIC (EDAC): Look, absolutely. I think - - -

MR WALSH: Plus innovation.

DR SOLDATIC (EDAC): Yes. I think the distinction though is having services that provide for people with disabilities to having services that are provided by people with disabilities. Of course there is a reality where this isn't going to occur in people with disabilities running the services completely. But we need to ensure that there are a range of safeguards embedded within the regulatory framework that the voices of people with disabilities are actually responded to both individually, as a person receiving the service, but also collectively. So how does their collective voice inform the structural organisation in the delivery of those services to improve overall quality of care?

MR WALSH: Thank you. I just have one more, Patricia, not so much a question as a comment, that we actually haven't had very many presentations from representatives of non-English speaking background, culturally and linguistically diverse, so any literature or advice you can give us on how best to understand those issues of disability in those groups would be appreciated.

MS YEONG (EDAC): Can I just add that it will be in our written submission, and if you refer to our previous submission there are lots of material relating to the barriers and needs of people from CALD backgrounds and non-English speaking.

MR WALSH: Thank you. Thanks, Patricia.

MS SCOTT: Thank you. I'm conscious that I will try and stay on time.

MS YEONG (EDAC): Can I just finish the two points?

MS SCOTT: Sorry, yes.

MS YEONG (EDAC): Are there questions to them?

MS SCOTT: Yes, there are. I have got some further questions.

MS YEONG (EDAC): Yes, okay.

MS SCOTT: Do you want to state something?

MS YEONG (EDAC): I just want to finish the two points.

MS SCOTT: Yes, please.

MS YEONG (EDAC): Yes, we are co-presenting. They left me last with two points and I really want to bring it up before we have overall discussions. The two issues I want to raise are one relating to rural and remote regions, that include regional areas as well. The other one is related to aged care and disability. I've got personal comment on that one with regard to my own personal situation.

The first one with rural and remote areas, I think Brian has mentioned that earlier too, to look at the distinct disadvantages of people in the remote regions. I think they need special consideration based on the isolation, the remoteness - it's really limited services up in the remote regions. We know some of the issues because we have an advocacy service in Carnarvon and one in West Kimberley. We are actually waiting for the reports from our staff members. They have done consultation yesterday and next week. We hope to incorporate it into our report. So I'm just going to say that it's really special consideration given the remoteness. Given the workforce it's difficult to - even you have a care package - to find work-appropriate and competent people to deliver the services in remote regions. That needs to be taken into consideration.

MS SCOTT: Yes.

MS YEONG (EDAC): Again, with the geographical coverage of Kimberley - I think it was raised by Brian - can I just quickly mention, for disability and aged care, in your report you refer to choices; that is also about people with disabilities going into the transition to 65, aged care and retirement. We offer choices A and B, and our preferred option is really B rather than A. I think people should have a choice to remain in the NDIS and not to be automatically transferred to aged care services.

I have got a case situation where someone is a paraplegic and they are independent for over 30, 40 years. Unfortunately, he has a stroke at the age of 65 or 68 and now he is in an aged care facility, which is really inappropriate for him. He is still very acute and very aware of the situations but, being in an aged care facility, he is really vegetating in there. We don't feel it's appropriate for some aged care services to provide and understand the disability needs, particularly the paraplegic where there's a requirement of bowel control and bladder control, which a lot of aged care services don't have the knowledge for. His recreation activities are actually nil; he's just sitting there. It is a personal concern. I will be entering retirement age and I am worried that, if I have to, when I retire, I'll be forced into an aged care situation and support under aged care. I just don't feel comfortable for myself and I don't think they are adequate to meet my needs.

I've worked for 30 years or more and I have some savings, but that's not going to be adequate for my retirement. I also have an issue with co-payment: when the NDIS refers to universal and not means-tested, there is also a co-payment component which, I think, needs further consideration. It hasn't taken regard of people with disabilities who has the added cost of disability. I think that needs to be considered. I know I'm rushing it through, because I know you have questions at the end. I'm going to leave it at the moment and wait for your questions.

MS SCOTT: Okay. Thank you very much for coming along. We do appreciate that. I've got quite a few questions and I'll try to be brief. Jenny, because you started off saying it's a very large report and you haven't had the opportunity to get all the way into it, I'm conscious of that and in some ways it would be lovely to give organisations like yours more time to consider the report, but we've got acute deadlines that the governments given us and we must meet them. Please note that my preface is to the fact that I appreciate you haven't had time to necessarily get into the report, but that characterisation on the aged care: I understand that you - we set out two options. Just because other people will read the transcript, I just want to get it on the record correctly and then maybe engage with you.

The first option isn't that people are forced into aged care services - I think you said words like that - it is that at age-pension age they would choose where they would like to get their services from. An individual that's suffering early dementia may well want to choose services from the aged care sector, because the aged care sector can provide those services. The issue is with where the funding is coming from, that was the critical question; where should the funding come from. So just for the record, I just wanted to get that correct.

On the issue of the second option, and I think that's the one you favour, this is the idea that rather than funding coming from the aged care sector after age-pension age, with people being able to choose whether they want to continue with the services that they're receiving, from Perth Home Care, Yooralla in Victoria, or whatever, that in fact what would happen is that person would continue to receive services, if they wished, from the disability care sector. The assessment process would be the same but the funding would be a more complex exercise of trying to establish whether this part of the package represented the frailty because of your age, an aged element, and the other part of the package reflected the disability element.

The reason why we've set out two options is because we genuinely want to hear back from people. I'm very pleased that you've raised it and we'd welcome your input. We just know that the second option does exist in some countries overseas and in some schemes here in Australia that operate like that, where they relate to some of the no-fault compensation arrangements. But it does mean that you have to make quite acute and difficult judgments about to what extent does that reflect underlying disability and to what extent does that reflect natural ageing and frailty. That's why we just said it might be complex and difficult and a source of great frustration, but we hope to get lots of responses on that issue, because it is tricky one.

I wouldn't mind, if that's okay, now turning to Karen's presentation. Karen, you've given us a lot of food for thought. We would be very keen to see references to the international research; you talk about a substantial body of international research which highlights the dangers of going down the route of thinking that individuals will be able to have mobility when it comes to decision-making. I'd have to say, we've heard other testimony from other people that are very keen and looking forward to having the experience of being able to nominate who their providers are and being nominated. So you've referred to that work and you've also referred to the emerging international evidence about - these are not your words - but the domination of large providers moving from prisons and detention centres into disability care. We'd love to see the evidence on that.

DR SOLDATIC (EDAC):   Disability and aged care.

MS SCOTT: Disability and aged care; we'd love to see the evidence on that. We have got a quite substantial amount of material in chapter 8 on a quality framework. I won't read it out, it would take too long, but we have suggested complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations; the NDA monitoring compliance of these standards; regulations through a range of instruments, including graduated and rolling audits of service providers, community visitors, senior practitioners, independent consumer surveys - you were talking about, "Where's the feedback loop?" So independent consumer surveys, which are independent of the service provider. So someone asks you, "What did you think of that service?" That the information would be put up and transparent on the web sites. When people get to choose a service, they would know the star ratings of those services. Complaints mechanisms; surveillance by case managers; and interrogation of electronic disability records, so that people could see whether they were overservicing, underservicing, were there complaints about this particular provider.

We've even talked about penalising providers for inappropriate services and effectively ceasing to approve a provider or service provision in the case of ongoing complaints. But if you don't think that's sufficient, we'd welcome further material about what you think there should be. I just wanted to provide, for transcript purposes, that sense that we haven't ignored this issue.

DR SOLDATIC (EDAC):   I guess I'd like to clarify though, we're not actually against individualised funding, we feel that's a core part of the component but they have to go and use that funding. In most cases they will be purchasing support services from services. So our interest is, when a person goes and does that, what is the governance framework to enable participation within the decision-making process in the organisational structure of that service for end users? It's not just providing governance oversight, but it's actually active engagement of end users within the organisational structure itself.

MS SCOTT: You think that would be more effective than people being able to - that's quite a time-consuming thing, someone being on a governance structure for each institution that we're talking about, each service provider, mainstream service providers, specialist service providers, versus being able to just simply say, "I want to be able to hire my own staff. I want that attendant carer. I don't want that person. Don't turn up at 11 o'clock because I want someone at 9.00. I'm going to a wedding, I want you there to be able to assist me then. That's not good enough service, you don't respect me." I'm just trying to get that sense of - in normal consumer activity I don't need to be on the board of the next restaurant or cafe I go to, I just need to know that the services are good enough and if I don't like them, I'll walk out on them.

DR SOLDATIC (EDAC):   I think when it comes to care markets there's a particular level of vulnerability, lack of information available to people. For example, I was at a forum yesterday and there was a woman there with a disability and she was just relaying a story to us about how one of her friend's main carers was her partner, was quite abusive. So in that situation she doesn't have - he might be the person who is controlling the money. So I mean information - she is not going to have access to that information. So in those situations it might not be in the person's interests to actually have individualised funding that's portable. It might actually be in their interests to have it provided through a service so there's some kind of mediator between that person and the partner. But also in that situation she couldn't just pick up and leave and purchase a different service per se because of the partner being the controlling entity within the relationship.

So I guess for me what is a bit problematic throughout the report personally is the assumption that all informal care relationships are going to be okay. But actually there is substantial evidence to tell us that both informal and formal care relationships for a lot of people with disabilities are not as open and transparent and democratic as we hope them to be. So, therefore, whilst we fully support individualised funding and, yes, there are a group of consumers who are going to be able to engage in the care market with absolutely no problem at all, we need to recognise the vulnerability of other people who are going to have to be reliant on care services as a service where their money is given to that service, such as outlined in the report, and then they engage with that service.

But how do those people have access to advocates, external advocates, and support that can support them engaging with those services? But also in maybe personal relationships where who is the controlling partner in those engagements. Also if they're living in a group home, for instance, how will they have access to alternative information because the group home is governed by the service? So it's about opening up those services so there's a bit more end-user engagement throughout the service.

MS SCOTT: Well, thank you for that clarification, it's very helpful. John, I think I might wrap it up there. Are you comfortable with that?

MR WALSH: Thanks, everyone.

MS SCOTT: Thank you very much for attending today.

DR SOLDATIC (EDAC):   Thank you.

MS SCOTT: I now welcome to the table Samantha Jenkinson. Thank you very much for coming along and thank you for providing some notes to us in advance. I appreciate that I'm well and truly behind schedule now but don't be worried. You've got 20 minutes for your presentation and for us to ask you questions. So please commence when you're ready.

MS JENKINSON: Thank you. Samantha Jenkinson. I probably won't take that long, and I'm sorry, my notes were actually just sort of yesterday that I sent them to you. I think, like Jenny, the 800 pages is a lot to go through. So I don't know it all, but I've been popping back and forth through bits of it.

Firstly, I wanted to say that I think there are some really great things in the report. I think that the report has really shown that the Productivity Commission has really listened to the submissions that have been given. I think it's a really good report, so I wanted to start out by saying that. In particular, the recognition of people with intellectual disability as a group that needs ongoing support is really great to see. The recognition of personalised and individualised support as the best way to meet the needs of people with disabilities, again, really good to see that in there. Having the sort of funding and decision-making in regards to disability support and ability to cash out packages I think is really great.

I think the keystone of it all, which we loved to see, was the legislative formula and quarantining of funds for disability. If nothing else that would be the one thing that we would want to see government do, and also things like the recognition of the need for community awareness an capacity building. So some of the key points that I've got which I wanted to raise today are - I guess some of it is around some of the detail but some of it was also around the broad conceptual stuff as well which I know Karen was raising.

So the first point I wanted to make was about the connection to the United Nations Convention on the Rights of Persons with Disabilities. One of the things that we have been hearing a lot in discussions I've had with other people was people looking for where is the values framework and the values base to the report. I think when I've gone through it I've found that it is in there, you know, when you talk about giving people power and choice, but it's hard to see how it's consistently in there because there's not that direct connection to an overarching set of principles and the UN convention in particular.

So it would be good to see that sort of be a bit more sort of in there. Where it fits in terms of - and I know, because it's a report for government not a report by government, it's hard to necessarily see where the framework you're talking about sits within the rest of government processes but it would be good to have some ideas around that. So, for example, one assumes that it will be connected to the National Disability Strategy and that has the principles of the UN convention as its guiding principles. So it would be again nice to see that in the report that those connections are made.

Also, I wanted to talk a little bit about outcomes. I think the term "outcomes" as used - and I actually struggle with that a bit because my key thing is, "Well, but who decides what the outcomes are? Whose outcomes are they?" I think that connects to sort of what Karen was saying in terms of the engagement with people with disability and knowing well, what are the outcomes people with disability want, not just what is the outcome that is an agenda of government or an agenda of service providers. I think a really good example of that is the debate around employment where sometimes the actual policy and practice is about the outcome of reducing numbers on the disability support pension, not about the outcome of people with disabilities getting a good job. So I think that's important that we're not just using the word "outcomes" but actually it has a meaning and that meaning is based on what people with disability want and what is going to be the best outcome for them, and keeping that clear.

I have made a few points in the dot points that I've got which are about the engagement and involvement of people with disability in the design and implementation of the scheme as a whole, but there are some particular spots where I've talked about, in particular - so I'm going to jump a little bit with the list I've got there. One particular part was in the development and design of community awareness campaigns. I think that it's really great that it's in there but I guess there has, for example, been a lot of debate recently around television ads done by different service providers, some which show people with disabilities in a very positive light, some which show them in a very needy, dependent, not so nice way of viewing people with disabilities. The big difference between those ads when you've gone into it is where were the people with disabilities involved in the design of those? So I think that's a really important part of any community awareness campaign.

But again, I have a point around assessment, the assessment and person-centred planning and I'm just going to jump to that now. One thing I found was that the chapter on assessment - I found it quite confusing. I would like to interpret it as there being an assessment process which was about your eligibility and that the person-centred planning - and the planning part of it is about the funding and what supports you might need. But I'm also worried that the other interpretation is that that's all in one package and that the sort of assessment tools you're talking about are functional based for a reason but actually missing that aspect of person-centredness. I'm not sure whether the idea of what person-centred planning is about has really gotten into what is in there. It's quite difficult.

So I wonder if maybe it's an area where you don't want to go into too much detail and in fact the recommendation might be better to be that the implementation of that is actually worked out with people with disabilities, families, carers and some expert groups rather than trying to do it all in the report that you do, because I don't know if you're going to get it, because it's quite complex. That's not to say that you're not very competent people.

MR WALSH: Can I just comment on that one, Patricia?

MS SCOTT: Yes, please do, John.

MR WALSH: I think this is a really difficult one, Sam. I think almost by definition if we have a scheme that has resource allocation based on support need then that support need be part of the eligibility process. That might have to be manifested in some cases in a diagnostic categorisation process, intellectual disability, but it doesn't, I think, detract from the idea that what we're trying to achieve is that those people who need the support are those who will be eligible to get support through the system.

When it comes to the planning of what those supports look like, I think that it's likely to be a very - and I think what we're trying to achieve is to come up with a support package which is appropriate to the person's needs. But how that package might be used, expanded, is a very individual thing. So it may be that as you say the report is not particularly prescriptive on that. I'm also not sure that it can be decided by a group of experts. Each individual might have a different personal plan for how their support needs might be met.

MS JENKINSON: I guess what I'm saying is that the report isn't very clear about that, I don't think. When you talk about the assessment tools and things like that you've got things like how long the assessments might take. My experience of good person-centred planning is it takes a lot more than a one-day meeting. It's something which can be, depending on the level of a person's disability, quite a lengthy process in terms of 40 hours or more of someone being involved with that person and their family and their support networks to help develop what the plan might be. It worries me that that might just get all be put into a two hour assessment process.

MR WALSH: Yes, thanks for that.

MS JENKINSON: My reading is that that's not quite what you're saying but I don't think it's very clear.

MS SCOTT: No, I think you're making some good points here, Sam. We do struggle in various parts of the report about - you know, the temptation is to think that you're going to write the manual for the people who are going to implement it. But I think, no, that's not our job. Our job is just to work out what is feasible and to give enough confidence to people about how we think it could operate. There's a lot of good people that would need to be involved to then take it to the next stage. So possibly in chapter 5 we're diving into detail and other times we're staying at the very level and trying to avoid that temptation.

In some ways the reason why we detail in parts of chapter 5 is because people know that assessment is critical to the whole exercise. So just saying, "Look, a group of people who would be interested in this topic and competent will work it out later," just didn't seem to be good enough. But, look, I would welcome - and I know we drew on your earlier submission, as you would have seen in the report - what advice you could offer us on this to make it clearer about the goal of the individual being reflected in the outcomes that people are seeking, that would be useful. But I think the danger of us having a throwaway line would be very dangerous for people's confidence in that they - you know, the confidence they could have about, "I think I know what they're proposing," therefore, "I like it," or, "I hate it."

MS JENKINSON: Yes. I'll just keeping moving through. I'll try to be fairly quick. I wanted to, in particular, talk about employment. I think that when reading the report the employment issue is quite - again, an area where there's a bit of fuzziness, in that in one area you talk about employment services being a mainstream issue but providing support for specialist employment services. I guess it's unclear as to what is a specialist employment service. We have specialist employment services through the disability employment services that are run by DEEWR and then there's the Australian Disability Enterprises' supportive employment services run through FaHCSIA. The evidence shows that good disability employment services that are getting people work and providing the support to be maintained in that job, wherever that job might be - you know, there's evidence that that works.

I point to Jobsupport in New South Wales, which is a disability employment services, not an Australian Disability Enterprise, that supports sort of 500 or more people with intellectual disabilities into open employment earning decent wages and that's where we like to see the sort of changes in something like the NDIS and that supports that could be provided are being focused on rather than other models. My understanding is that the report talks about things like personal care support, and it doesn't matter where that might be. So if you're working and you need personal care support, then you can take that personal care support with you to work.

But then for someone with an intellectual disability, if they need other types of ongoing support to access the community - and that might be support in terms of social support or remembering routines, or things like that - if they need that support, whether it's to access the community or to have a community support option or to be in an Australian disability enterprise or to be in an open employment job, then the same logic should apply. What I'm reading in the report is actually that you're still maintaining the silos that are there for employment for people with intellectual disability, but not for people if personal care support is the only support they need. I know it is one of those fuzzy areas.

I talk about disability expertise established in mainstream mental health justice and other human service areas and I guess it's that same thing, in that people's lives can be quite complex. One of the big things that I think many people were hoping for was that the framework that we're talking about for a national disability insurance scheme would help to de-silo some of that, and you recognise that in the report, but then there are some specific areas, like the employment and like accessing health and mental health, where people have dual diagnoses, where people have extremely complex interactions with multiple systems, and we don't want that to continue in those cases.

I will move from employment to what I mean by that. You talk about the tier 2 information and referral specifically and memorandums of understanding. I think that one of the areas which was a bit fuzzy for me was whether memorandums of understanding in themselves were actually enough, and I guess this is about how what we are talking about in this system links to other things, like the national disability strategy, because often it's not so much that people might need a referral to another service but that the service that you're talking about, so the health system, doesn't have the expertise in it to understand the disability issues that they're being asked to deal with as part of what they need to deliver as a mainstream service.

A lot of the states have projects, like in WA there's the exceptionally complex needs project, there's other states with multiple complex needs projects - and people who cross those different sectors are needing actually this extra support which involves all those different groups, and that's one of those things which currently involves state-level disability service systems, which we wouldn't want to lose in shifting to a different framework, which currently involves state-level disability service systems interacting with those other services. So it's that interface between the different services.

I'll move on to the housing. Again I think using the term "specialist accommodation support" is a bit like talking about specialist employment support. It feels a bit like you have sort of bought into the silos that are already in existence rather than trying to get rid of some of those things. One thing I was hoping to see in the report, which wasn't there, was the separation between the support people need to live in whatever housing choice there might be, the rental or the bricks and mortar part of it. I understand totally that we need way more housing.

One of the issues that I have and many advocates have with some of the models of housing that are currently around and that we were hoping to see less of in the future is where a person is a captive audience in having both their landlord and the support provider as the same person or the same organisation, and I don't know that that is necessarily dealt with where you have looked at specialist accommodation services. I was hoping to see something more that was about the support people need to live, and then, "Yes, there needs to be money and funding put into capital for there to be more housing." But I actually see it better that that comes through community housing providers or social housing providers rather than it always being in the one package, because I think that, yes, people are captive in that.

MS SCOTT: I am a bit conscious that, because I allowed some other people to go over time, we are going to press up right against lunch.

MS JENKINSON: The only other thing I wanted to do is echo submissions on the involvement of people with disability at all levels. I don't think there's meant to be an assumption or expectation that there aren't people with disability who have the skills and abilities to be on the governance board, but sometimes it's the way it's written that brings that across. Again the better connection between the advisory board and the governance board. I would be strongly pushing for a majority of people with disabilities on the advisory board and that there needs to be people with disability on the governance board, because that is what this is about, people with disabilities, not service providers or government bodies.

MS SCOTT: Thank you very much. John, any further questions for Sam?

MR WALSH: No. Thanks, Sam.   That was very helpful.

MS SCOTT: I now ask for Senses Foundation to come forth, please. Good afternoon, and thank you for coming along today, Debbie. Would you like to commence your presentation. We'll go into lunchtime. I'll have to work out how we're going to manage lunch, but let's proceed.

MS KARASINSKI (SF): Okay. I'll be super quick, because we're also putting in a written submission. I need to tell you I have got a hearing impairment. I'm having a lot of difficulty hearing both of you, but particularly the associate commissioner when I can't see his mouth. But if you could interpret for me when we get to that point.

MS SCOTT: Okay.

MS KARASINSKI (SF): Like other presenters, I would also like to congratulate the federal government. It's exciting to imagine that the federal government and the Productivity Commission have actually considered the needs of people with disabilities, and the fact that people are sitting over there talking about this issue is tremendously exciting. While we would support many of the commission's recommendations, we just want to comment on the NDIS as a whole, some of the issues or concerns that we have got, and then make comment about the needs of people who are deafblind, which is our area of specialty I guess. I know it's micro as opposed to the macro that you're looking at, but in doing so I think it will raise some issues for a number of people with disabilities.

The first issue for us in the NDIS as a whole, one of the things we are concerned about, is that in trying to establish equity for people with disabilities throughout Australia we are just concerned in Western Australia that we don't throw the baby out with the bath water, so to speak. I'm not suggesting for a minute that Western Australia has got it all right; we have heard this morning lots of issues in relation to where we haven't got it right. But we have got some things right. We'd really like to see that the needs of people with a disability are actually dealt with in a manner that our services are built on, rather than thrown out nationally.

So that's the issue for us in terms of disadvantage perhaps of equity across the states. The second one is a national system versus a state system, and you will hear that a lot from Western Australians, but we are a heck of a long way from the eastern states, and that opportunity to talk to politicians here about issues that pertain to Western Australians, to talk to administrators here about our concerns, to be able to just sort of run up the hill and talk to people is a real advantage of a state system.

It's a heck of a long way and a heck of big expense for organisations like ours or individual people or their advocates to actually get across to the other side, and we always feel there is that perception that Western Australians do not as well under a national system. From Senses Foundation's perspective, we are an aged care provider, we have been an employment provider and we have worked in those national systems. So whatever system we end up with, we'd really like the opportunity for some decision-making at that state level, some consideration that that tyranny of distance is taken into account.

All the rest of the issues relate to understanding deafblindness, and again I appreciate that this is a micro issue for the Productivity Commission, but we are concerned - and I know you couldn't use all people with disability - that there there's lots of examples from disabilities that are well known and well understood but not a lot in people, for example, who are deafblind. Back in 203 in Western Australia we had 8800 who were deafblind. Over 2000 of those live in rural and remote Western Australia, many of them are from indigenous populations, approximately half with profound and severe levels of disability.

So we're talking about a group of people with high levels of disability, high users of services for people with disability; and an increasing population of people who are deafblind, not a decreasing number. The indigenous communities arr more at risk of deafblindness. Indigenous women in rural and remote communities have inadequate immunity to the rubella virus; prevalence of foetal alcohol syndrome is very high, impacting upon Aboriginal children; prematurity is common in indigenous babies; higher rates of diabetes are demonstrated in indigenous populations. One of the areas where I don't think we do very well in Western Australia at all is dealing with rural and remote communities.

Draft recommendation 3.1, programs benefiting people with deafblindness, but not provided directly to the person who is deafblind, one of the services that Senses Foundation provides is training, resources and support to Aboriginal health workers, to health professionals, to medicos and others in rural and remote Western Australia, but the person with the disability is not there at all; it's to the service provider, in order that they have the skills to be able to provide the service to the person who is deafblind. We're concerned that the education training and resources programs like that which don't actually have the person with the disability directly involved may have no means of funding under the proposed NDIS.

MS SCOTT: Okay. I just want to check that I've got this point because it seems a very important one. What you're drawing attention to is the fact that your organisation provides services to services providers in terms of training and education so they are then able to provide better services to people who are deafblind.

MS KARASINSKI (SF):   That's right. We do it in the metropolitan area to, for example, nurses at Princess Margaret Hospital, but we also do it in rural and remote communities and we're concerned that the funding of those sorts of services - we're not sure where it fits under the proposed NDIS. The next one was in relation to recommendation 3.2 which related to that early intervention and clearly early intervention for children who are deafblind, we can see that fits directly into the sorts of recommendations that you have been making.

But for some of the conditions that present - and I'll give an example with Usher syndrome, a person is born deaf or with profound hearing loss and then develops blindness in their teenage/young adult years. We're concerned that those people with Usher Syndrome will need early intervention services even though they're in their teenage years and early adult years. They would already be accessing services for their deafness but they need early intervention deafblindness services and we're just concerned that those sort of people might be overlooked and might not fit to the early intervention definition.

MS SCOTT: Just to clarify that, because again other people will read the transcripts and I don't want them to be in any state of uncertainty, we indicate elsewhere in the large report that we don't want people to think early intervention means always young children, it could be at different points of transition, it could mean shortly after diagnosis or when a condition deteriorates or when a person reaches a different stage in their life. Debbie, you will be pleased to know that some people with Usher syndrome actually presented to John and I in Melbourne and we looked at a range of issues with them, including availability of new equipment. I just thought you should know that early intervention doesn't mean just once and just when they're under an arbitrary age. It's not like that at all.

MS KARASINSKI (SF): I did read that in relation to multiple sclerosis but wanted to clarify it also with Usher. The other thing in relation to people who were deafblind, we were just concerned about the words "reasonable and necessary" and the next layer or the next group of people that look at what services will be reasonable and necessary for people with a disability. Some of what we would consider reasonable and necessary services for people who are deafblind are not necessarily obvious and, you know, anecdotally my friends say, "What does an occupational therapist or a physiotherapist do with a person who is deafblind?" and my example to them is, "You just watch how a baby responds. They respond to noise, they respond to vision."

So a lot of our programs relating to babies, relating to children, relating to young adults require physiotherapy, occupational therapy, social work services, psychology services in some cases. So when we get to that point of actually defining what is reasonable and necessary we need to think broadly but then specifically in relation to those needs of those particularly unique groups.

MS SCOTT: We are proposing not only to use allied health professionals but those trained to think about reasonable and necessary needs, wouldn't that provide you the comfort that a well-informed assessment workforce would be thinking about that physiotherapy may be required because they're not getting the same stimulation from sights and sound? Doesn't that provide you with comfort, the fact we're not using lay people to do assessments?

MS KARASINSKI (SF): I hope so. In a way it does. I think there is traditional disability and I think it will be good at that. I think that some of the very unique and special disabilities and also low-incidence disabilities like deafblindness, I think we will really need to target some of the again, reasonable, necessary or very specific needs of that group to actually get it right and meet their needs.

MS SCOTT: I guess this is where training modules - we talk about senior practitioners in the report. In Victoria they have a concept of senior practitioners, people who stay up to date with latest clinical practice, latest therapies and so on, so they can be a resource for the sector to ensure that people aren't just doing things a certain way because that's the way they learnt it at university 15 or 20 years ago. I know that Commonwealth Rehab Service - which has services at Kununurra and Broome and so on - they have a process of ensuring latest practices are infused in their staff and the people don't lose the cutting edge on proven clinical practices when it comes to therapy arrangements. So maybe that's something that we can spend a little bit more time on in terms of the report. Your point is well made. Thank you.

MS KARASINSKI (SF): That actually fits with my next comment which was the opportunity to introduce new and innovative services. One of the deficiencies in Western Australia is that you come up with a completely brilliant and innovative service but it's very difficult to stuff it into the system. We at the moment have a pilot project in Western Australia for people who are deafblind using communication guides. Communication guides are called interveners in Canada, they're communicator guides in the United Kingdom and they're called contact persons in Denmark. People who are deafblind use these people - they're intermediaries between the community and the person with a disability.

They don't exist at all in Australia at the moment. We've got a pilot project happening her in Western Australia. So if we do find that they meet the needs of people who are deafblind, then we would like an opportunity somewhere in that NDIS to actually get them into the system. We wouldn't be unique in that. We don't have such a rigid number of services that we can somehow or other get these sorts of services in.

MS SCOTT: Yes. We talk about a innovation fund in the organisation. I think that would lend itself to that. We would be happy to take your material on the communications guides.

MS KARASINSKI (SF): Further to that, we note that you talk about funding services that have been demonstrated to be effective and certainly in deafblindness we have an absolute paucity of services that have been determined to be effective because of the small numbers but also the fact the deafblindness has only been determined to be a unique disability for a short number of years. So we are very pleased that you are going to support research and we really hope for that opportunity for those services to get into the NDIS as we proceed.

The final comment that we want to make relates to sibling support and Carol Franklin talked about that and we want to really support her comments. We run a sibling support program, a very highly valued service. Siblings have been demonstrated to be one of the longest lasting relationships for a person with a disability and we believe that if you really support and develop that relationship from a very early age, that it is a very positive relationship, there is a greater likelihood of that continuing into the future, you know, long after mum and dad are no longer around.

We are concerned under the NDIS as it is proposed at the moment that again that funding is not available, may not be available to support the sibling of the person with a disability.

MS SCOTT: Where do you get the funding currently from, Debbie?

MS KARASINSKI (SF): From philanthropic groups because nobody else will fund it at the moment.

MS SCOTT: Okay. I'm sure you could tell that I was taken by what Carol said this morning because we had used the phrase "carer" or "carers" and I know siblings could be but I thought a key point that she made this morning and resonated terribly well was that maybe we hadn't set our sights wide enough in terms of including siblings. Again, if there is material you could provide on support programs that you provide, I would be very interested to see them.

MS KARASINSKI (SF): Yes, I would be very happy to do that. These littlies share all the same concerns as mum and dad, they have the same levels of anxiety, they need support. I wouldn't like to see them grouped with carers so much. Carers have very special needs. But the siblings of the person with a disability have very special needs too. Our sibling support program is - you know, many of the things that Carol said, that the child is seen as special too, they're given a lot of the skills, they're encouraged to develop networks of their own and certainly in the case of deafblind, unless it's facilitated by an organisation like ours, they may never meet another person who had a brother or sister who is deafblind and it really makes a difference not to feel all on your own. That was our final point. I tried to be as quick as possible.

MS SCOTT: Thank you. John, do you have some questions, Debbie?

MR WALSH: No, thanks, Debbie. It would be difficult, I think, from here and I think you covered it pretty well. Just one actually, I think you said there were about 9000 people in Western Australia with deafblindness?

MS KARASINSKI (SF): There was at least 8800 back in 2003 with the census.

MR WALSH: Do you have any feel for the age distribution of those people? I know you talk about Usher which comes on in teenage years.

MS KARASINSKI (SF): Yes, we do. I don't know them off the top of my head but our study which is called Unseen and Unheard which was done by the Telethon Institute for Child Health Research for us I can make available to the Productivity Commission.

MR WALSH: Thank you.

MS SCOTT: That would be very useful. Thank you very much.

MR WALSH: Thanks, Patricia.

MS SCOTT: I'm just reviewing my notes, John. You made the observation at the start that you're very keen not to lose the strengths that are in the Western Australia system and we have tried to acknowledge that there are strengths in a number of jurisdictions. New South Wales is particularly good in terms of initiatives on transition to work; Victoria has probably gone further than most states on real individualised funding packages with choice; each jurisdiction has their strength. It would be useful if you could indicate those things you are keen to see retained.

On the point of tyranny of distance and so on, your points are well made. We had proposed a regional structure for service delivery and that there would be decision-making at the regional level. I think it would be very unwise to have decision centralised in any particular location. People on the ground are more likely to get decisions right than someone 1000 kilometres away or even 500 kilometres away. So just keeping that in mind maybe you can think about when you finalise your - - -

MS KARASINSKI (SF): I interpreted that in the report as decision-making around the individual person with disability locally and I think that is absolutely great. Decision-making and policymaking is, I guess, what I'm talking about, that somehow or other that be decentralised and that administrators here are able to make some policy decisions about service.

MS SCOTT: All right. Thanks for that. I guess you would have seen a length section in chapter 7 about the strength and weaknesses of various approaches but thank you for making that point. I think we might break for a well-deserved lunch break and we'll come back at 1.35, please.

(Luncheon adjournment)

MS SCOTT: Good afternoon. Welcome to the table United Voice and for the process of the transcript, could you identify yourselves, please. We have assigned 30 minutes to your presentation, so don't worry about the fact we have started a little late. Please allow some time for John and I to ask some questions.

MS SHAY (UV): Thank you, commissioners. I will just begin by introducing myself. My name is Kelly Shay. I'm the assistant secretary of United Voice in Western Australia. I'll let my delegates introduce themselves and maybe where you are from as well.

MS VOAK (I): My name is Wendy Voak. I work for Identitywa. I've been there for 13 years.

MS SUMATA (AA): My name is Carol Sumata. I'm a direct care worker with Autism Association of Western Australia. I have been there for 15 years.

MS BARNES (TCCP): Hello, my name is Dianne Barnes. I'm a team leader for Cerebral Palsy and I also work for Nelson. I have been a direct care worker for just over 20 years.

MS SCOTT: Great. Please call us Patricia and John.

MS SHAY (UV): Thank you. We would like to start by thanking the commission for the opportunity to present to you today. United Voice put in a submission I think in August or October last year focusing on wages issues and workforce issues and we have also just as late as yesterday afternoon put in our submission to the draft report. I'm not sure whether you have received it but we will talk in general to that but that has been posted to the Productivity Commission.

United Voice represents and actively represents disability direct care workers across Western Australia, South Australia, New South Wales, the ACT and Tasmania. We have a significant membership in this area and our members in Western Australia count to over 1000 members in the non-government disability sector. We appreciate the opportunity to give the submission today and we welcome and support the recommendation to introduce a National Disability Insurance Scheme. We are disappointed, however, in the draft report to date and its lack of anything actually significant to deal with workforce issues. As a matter of fact the content of the draft report today is disappointing because it does not address the major workforce issues that we have previously identified in our past report and which we will again report to you today.

So today we are just going to focus on recommendations covered in section 13 of the draft report and I am going to hand over to our delegates to cover those key issues such as the ageing workforce, wages and conditions, respect, recruitment and retention, the need for police clearances, a mandatory entry level, training and development and ensuring that there is an adequate career structure in the industry.

If I can just begin by talking about wages in this industry. The non-government sector in Western Australia is significantly underpaid compared to the government sector and this is a trend that is consistent across the entire country. It is not special to Western Australia. We have a minimum of 30 per cent disparity between government and non-government direct care workers which means that our members in the non-government disability direct care industries, predominantly working in residential homes, are working at 30 per cent less pay than the government sector.

The Western Australia state government has a clear agenda to continue to outsource disability service commission places to the non-government sector and increasing that workload. We also understand in the state budget that there should be or we anticipate in the state budget there will be some increase to the non-government essentially as a sweetener, we think, by the government to encourage non-government disability providers to pick up additional places. We don't think it will actually address the pay disparity between government and non-government workers and we think that the National Disability Insurance Scheme and any national inquiry into the disability industry needs to address the fact that we need a workforce in this industry that are adequately paid, are recognised as professionals and are paid a decent wage.

We still have in Western Australia a number of places where our members are expected to work night shifts or sleep shifts, as some people call them, who are responsible for four or five people in a home and who get paid as little as two or three dollars an hour, if at all, for being away from their home and their loved ones and being responsible for between four and six people with high needs and high disabilities. So there are significant workforce issues and we don't have the time to go through them in detail today and I would call on the commission to review both our initial submission and our revised submission. I will hand over to Wendy.

MS VOAK (I): Patricia and John, I would like the commission to look seriously and honestly at the ageing caring workforce. We here represent the vast amount of workers. It is unusual to see anyone below 40 and if you do they, like us, are dedicated carers with concern for the long-term welfare of our clients and the biggest concern being in us giving them the best opportunities for future development.

Through the use of modern technology and medication Australia has an ageing disabled population. We are in need of attracting and keeping young adults into the disability field now, not years from now. However, it appears this falls on deaf ears when it comes to remuneration for the dedication and amount of work that is done by carers for the disabled. It also devalues the disabled in our communities. We cannot compete with the mining sector. But why can we not be seen as leaders in providing people in desperate, vulnerable situations? Our clients need trained, caring and dedicated people who are there for them. We need a livable wage so we can stay there for them.

We ask on behalf of all carers that this commission look seriously at quarantining a large percentage of funding for direct care wages so that into the future we attract and keep a dedicated, well-paid workforce and that will reflect in quality of life for our clients. Should the majority of our clients be able to speak, they would endorse this. They need quality care and they deserve no less. Thank you.

MS SUMATA (AA):   As a direct care worker with 15 years' experience I feel professionally devalued and personally offended by the draft report's lack of serious attention to the workforce issues. I also feel that in stating that they need to keep wages low to reduce costs, as far as the insurance scheme is concerned, is offensive to me and that I am personally being asked to subsidise the scheme in a way. This idea that we can take in untrained staff to keep the costs down devalues the clients and the staff that are working with them. If all you want to do is babysit someone, you can have untrained staff. But if you want to teach someone and give them life potential and the ability to be personally responsible for themselves, then you need trained staff who can help them towards those goals. I don't babysit the clients I work for, I work with them to develop their life potential as far as I can.

Also the idea that we reduce the need for police clearances and that somebody has to identify when a client is vulnerable enough to need somebody having a police clearance to me seems preposterous because as far as I'm concerned all of the clients that I work with are vulnerable. Whether it be physically, financially or emotionally they are all vulnerable and they need all the protection that they can get and because they can speak or because they appear to have social skills does not necessarily mean that they full understand everything and we need to pay attention to that fact. They are different but because they're different doesn't mean they're of any less value.

If you reduce the need for police clearances, you open them up to abuse of a physical nature, financial and all sorts of things. That happens currently - I'm not saying they don't happen at the moment - but it is going to worse if we reduce the need for checking the staff. The idea that an advertising and media campaign is going to increase staff I think is - you may initially gain more attention and get more people applying for the job but if they don't have any training and they have no experience, they're not going to be retained and that would be, in some situations, abusive to the clients and the staff to put them in certain situations without training or experience. We are dealing with a vulnerable part of the community and we need to pay attention to these things. Thank you.

MS BARNES (TCCP): Hello. I want to concentrate on training and development and career structure. Our clients need to have and deserve to have trained staff. The last thing that a client needs is to have a carer who has had no training and not having any idea of how to use complex equipment. In this day and age and with excellent medical treatment a lot of our clients have very complex medical issues and we need to attract new and young people to our sector and offer them a good career structure with the ability to improve their career. To have a carer who is not adequately trained is not only dangerous for the person being cared for but it also puts the caring staff as well.

Employing families or friends to care for a disabled person to cut down the cost is also fraught with danger and with this type of carer, who is going to train them - not only for their own safety but for the client. It seems to be encouraged that they don't need to be trained, that they don't have to be trained. But I've worked with a lot of people that have really complex medical issues and a lot of complex equipment and there is nothing worse than going into a house or somewhere where they have some equipment and you have absolutely no idea on how to use it. I have seen the aftermath of someone being dropped and that client is never going to survive. Being a carer for someone with a disability isn't a babysitting position. It might have been 20 or 30 years ago where you just had to make sure they were clean, fed and put in front of the TV. It is not now. We concentrate a lot on goals for people and someone who isn't trained to do this is not going to know what to do.

People need to be trained to make this a highly professional position and we need to be recognised and paid accordingly. Attracting people who have no training whatsoever is not only detrimental for the person that you're caring for, it's not going to help the family and it certainly won't help our sector. It will only devalue us all. Thank you very much.

MS SCOTT: Thank you. Are we comfortable if we start to ask questions now?

MS SHAY (UV): Yes, please.

MS SCOTT: John, would you like to lead off on questions?

MR WALSH: Yes, I have a few questions, Patricia. Kelly, I just want to clarify, at one stage I think I heard you say that people were working for two or three dollars an hour.

MS SHAY (UV): That's correct.

MR WALSH: Can you expand on that a bit, please.

MS SHAY (UV): We can and we also draw the commission's attention to our initial submission which outlined very detailed examples of how it's currently operating in Western Australia and which providers are paying such rates of pay. Essentially because a significant part of the industry is award-free and we are working in residential disability facilities the concept is that it is a sleep shift so that they are often the only person there from 10 pm until 6 am or 7 am in the morning and during that period they're for some hours at "awake" rate of pay which is often about 14 or 15 dollars and hour and then for six to eight hours of the entire shift they are paid at what's called an "on-call" rate of pay and that rate of pay is between two and three dollars an hour.

We had a campaign about three years ago at one of the major employers, which was Identitywa and that was a particularly difficult campaign. During that time - and Wendy might correct me on the exact numbers - I think our members at Identity were getting paid $5.35 an hour for six or eight hours of their night shift. Through that campaign we ensured that they were actually recognised that if they're at work and they're responsible for the entire house, that they should actually get paid awake rates for the whole period. At Identity that is no longer a problem and we have a good collective agreement there. But that is an example as to where, as recently as three years ago it was happening.

In Western Australia there is 108 non-government disability providers. We have collective agreements in four and will soon have collective agreements in five of them. Those five represent 70 per cent of the industry. But there is essentially 103 other rats and mice where these types of conditions are prevalent in the disability sector and disability direct care workers are being taken advantage of and are expected to do this. There is only so much you can do for the love and the passion and the passion doesn't pay the rent.

MR WALSH: We had a presentation at the Sydney hearings from the Attendant Care Industry Association. Are you guys aware of them?

MS SHAY (UV): No, commissioner.

MR WALSH: They talked a lot about training and qualifications and very much about what people with disability need is a carer that is trained in the specific needs of that person. You gave examples of people with highly complex medical needs and certainly people need carers that have those qualifications. But many people don't have those very complex medical needs and we have heard over the hearings that what those people want are support staff with attitude and aptitude and I wonder if you had any views on that.

MS SHAY (UV): I thank the commissioner for the question and I think that there is clearly a need and in the draft report I think it's noted that there is a need for an acquisition of skills and qualification to promote career paths and we would welcome that. In terms of where there are complex needs of individuals, people with cerebral palsy or people with autism have very different needs, as two examples, and the staff who are required to care for and develop those people with disabilities should be required to have a minimum entry level and a career path and a structure. The current problem is that there is no formal career structure for those workers and there is no pay level that encourages workers to do that. So we would agree that there is absolutely a need for a career structure where there is a high level of need.

On the other side, where there is varying levels of need or varying levels of dependency, we still think that there are minimum entry levels that people should be acquiring to care for people with disabilities and I think it is too easy for people to say, "Actually that person with a disability's needs are not that high, they don't really need any qualified staff." I think we need to have minimum entry levels, minimum qualifications, no matter where you are working in the industry. I think that too often because it's seen as a caring role it's devalued and therefore people aren't required to have qualifications which just along in terms of the deprofessionalisation of the industry or the fact that the industry is not recognised as a profession.

But we need to find a balance where we can have - and I acknowledge there are differing needs of people with disabilities and we need to ensure that we can address both of those. So we need to make sure that we have a professional career structure and that we have training, development, qualifications, support and that people are obtain those training and qualifications because the currently the wage rates in the disability sector are so low that many, many people are working one, two or three jobs and low income workers can't afford to go out and spend hundreds of dollars or sometimes a thousand dollars to get additional qualifications in their spare time which may earn them, if they're lucky, an extra 10 or 20 cents an hour.

So there are a whole lot of issues there I know I am trying to cover off on in a quick catch-up. There is a need for both is what we are saying. But what is really crying out in the industry is a need to ensure that we've got professional, qualified staff who know the needs of the individual.

MR WALSH: That's great. So you acknowledge that there is a need for both levels of - - -

MS SHAY (UV):   We do and currently it's overwhelmingly that there are far too many unqualified people and we can't use the argument that some people with disability have a low level of need to justify maintaining the current status quo because the status quo is not working.

MR WALSH: I think you will find in our draft report that we do acknowledge that there is a great need for a career path for support workers. What we're hoping is that the opportunity - and all of you people who have made a presentation today have talked about helping your clients to build goals and plans and a life. I guess what our report is hoping is that increased funding and increased individual choice will allow that to happen. Do you have any comment on that?

MS SHAY (UV): I think what is missing from the commission's report is anything that actually addresses the wage crisis in the industry and if we're going to require more of people working in the industry, and we think you should - let's be clear about this, we are encouraging of a professional workforce, of recognising the professional role of our members. We also think that their wages need to be reflected to compensate for that and to recognise that level of care that they are providing. So we agree with the commission on one area, we just think you're lacking in terms of actually addressing the wages issue in the report.

MR WALSH: I'm just looking at your submission of last year and you do give what you recommend to be minimum hourly rates in that. Do they align with the current Fair Work wage case, do they?

MS SHAY (UV): Do you mean the ASU's SACS case?

MR WALSH: Yes.

MS SHAY (UV): I think they do. I'd need to go and check that and I will get back to the commission. I'm not exactly sure as that is being run by the Australian Services Union and we support the Australian Services Union in that pay equity case. I would like to go back and check that before I confirm it for the commission.

MR WALSH: Okay, thanks, Patricia.

MS SCOTT: I think I would like to, just for the transcript purposes, clarify just a few points that you made. For example, we have dealt with the issue of higher wages as a means to draw more staff into the sector. We have addressed the issue of career paths. We do promote the opportunities for better working conditions, including more favourable shift lengths to increase the number of people who would be attracted to the industry. Your points about people with complex medical needs requiring trained staff, I'm not aware of anything in the chapter or the report that would suggest otherwise. What we do say, and drawing on the evidence of people who provided testimony to us in person, is that they would prefer that they had choice over who their staff was and that they would like to be able to train staff in their personal needs rather than have someone come along with a certificate III who has not necessarily the right attitude or aptitude.

So I think we, as a commission, have to balance the diversity of views in the community and that means that some people who are fully and mentally competent do think that they can make the decision themselves about who they hire. But I take your point that if someone is autistic, non-verbal, has intellectual disabilities maybe they are not well placed to be able to make complex decisions about staff requirements. But I think you're characterising some of our statements as if it was applying to people in those conditions and it clearly wasn't. So I think we have to acknowledge that.

On the issue of training, the chapter does deal extensively with training and talks about the need for arrangements to consider the training needs for individuals depending upon the level of care. I think we could be clearer in this chapter, however. We have had a number of other people raise with us that it's almost as if there needs to be a graduated level of attendant care supports. I thought a clear message out of the report was we do expect wages to increase. They will have to in this sector in order to attract workers over time. So I think that you were applying sometimes a very broad brush to some of our statements and for the transcript purposes, I think I would encourage people to have a look at chapter 13.

MS SHAY (UV):   Commissioner, if I may, in response to that, there are just a couple of items. In our report we are making some pretty quick statements here. In our submission, the submission that you may not have in front of you because it was only presented yesterday, we have gone into these in a significant level of detail and we have given specific examples in that report and I would encourage the commissioners and all parties who are interested to read that report. I would like to touch on - and I am happy to come back at the end if that would be more convenient for you - some of the challenges that are faced when we have people with disabilities or their families directly - and we're not saying we're opposed it - employing their carers and some of the challenges that faces for the workforce and it's not to say it should not happen, I just think we have to come up with a new way of ensuring there are safeguards both for the person with the disability, so they have the opportunity to choose.

We absolutely acknowledge it is personal who is your carer. There is nothing more personal than who showers you in the morning, believe me we know, our members do it every day. But there are currently no safeguards in place to ensure that people are covered for workers compensation, that they're getting a paid a decent hourly rate of pay, that they're getting superannuation payments, that they're getting actual annual leave and the onus of every one of those items and a whole list more are based on that direct care worker. That is a significant onus we are placing on people. We need to see if we can find a way in which we can somehow make that easier for people with disabilities to facilitate. So we need to find a way to make it work for both parties.

MS SCOTT: I think that is a good point. We did hear some testimony - and I'm sorry, I can't pinpoint which city it was in - about someone who said that people do need flexibility, on the other hand they saw the need for induction training, that they saw the need for people to have over time OH and S training, they need to have their rights at work explained to them and so on. I welcome your submission, I just think it is in that area of us needing to reflect the great diversity of views about this topic that I would welcome your consideration of. I don't have any further questions for United Voice. Do you have any, John?

MR WALSH: No, thank you.

MS SCOTT: Thank you for coming along.

MS SHAY (UV):   Thank you.

MS SCOTT: Good afternoon. Thank you for coming along. Could you identify yourselves for the purpose of the transcript and then over to you, making your opening statements. We've allocated 30 minutes for your presentation. Please allow some time for John and I to ask some questions.

MS BATH (PWDWA): My name is Mary-Anne Bath and I'm currently the president of People with Disabilities WA.

MR JEFFERSON (PWDWA): I'm Andrew Jefferson. I'm the executive director.

MS DUFF (PWDWA): I'm Kerrie Duff, the senior systemic advocate.

MS BATH (PWDWA): We'd like to open our submission by welcoming the draft report and acknowledging the efforts to reflect the content of the submissions and the contribution made in the public hearings. It has been helpful, I know to many, to have the difficulties they have experienced through an unfair and underfunded system acknowledged through the forums that were previously held. The report has given many people with disability and their families and carers hope for more fulfilling lives in the future.

PWDWA supports the broad aims of the scheme described. It is recognised that there is much more detail to be developed and this will take time. PWDA recommends that at every stage of the development of the scheme that it includes the participation of and consultation with people with disabilities and their representative bodies. We see that as essential.

We consider that people with non-acute mental health needs must be included in the scheme. People with chronic health conditions must be included in the scheme. People with psychosocial disability must be included in the scheme. The scheme should meet the costs arising from the need of disability supports for people included in the scheme and not those that result from ongoing health and medical care.

PWDA supports the Western Australian local area coordination model as preferable to case management. The LAC, however, role would need to be extended to include a continuing relationship with each individual being assisted. At present, in some circumstances, that relationship ends when people go into certain accommodation. PWDA also accepts that there is a need for financial insurance and management expertise within the government's arrangements of the scheme. People with disabilities should be represented at every level of the scheme. There should be, at minimum, a commitment that people who serve to govern the scheme have access to ongoing disability awareness training so that both sides are supported to understand each other.

PWDA commends the proposed development of disability support organisations. We recommend that access should be available to the services of the DSO for all people in the scheme. We consider that the assessment model adopted will be a very important marker in the quality of the experience of the scheme for people with a disability and their family and carers. The outcome of the assessment will influence the rest of the person's life and impact on the lifestyles of everyone around him or her. People with disabilities and their representatives must be included in involving an assessment process that fits both individuals and stakeholders.

PWD recommends that the $500 waiver is removed from the scheme. It risks introducing unfairness into the scheme. It is a distraction from the broad aims of the scheme. The small financial benefit to the scheme does not justify the impact the payment will have to an individual. The waiver proposal has caused disproportionate concern to people we have consulted in relation to the draft report and distracted from the main aim of the report and the main body.

We are extremely concerned that the important role of independent advocacy is not reflected in the report. PWD considers that advocacy needs to be independent and free from conflict of interest. We consider that the provision of advocacy must be clearly separate from the provision of support services. Funding of advocacy services is essential in assisting people with disabilities to shape the future. Independent advocacy should be funded by the scheme but to maintain independence, it needs to have a line of accountability that is separate from the scheme. PWD is opposed to the idea that service providers should act as advocacy agents or advocate on behalf of people with disabilities as we see conflict of interest arising.

MS SCOTT: Just on the last point, Mary-Anne, are you stating that because you think that's what the report says or are you stating that just in case we go down that route in future?

MS BATH (PWDWA): I'm saying that in terms of reference to page 31 of the overview.

MS SCOTT: Okay, fair enough. On this point, a number of people have raised advocacy. Can I discuss this now?

MS BATH (PWDWA): Yes, certainly.

MS SCOTT: We have had a large number of people raise advocacy services with us, haven't we, John?

MR WALSH: Yes.

MS SCOTT: So I'd have to say there's a very strong message coming our way and we'll have to give it very careful consideration. But this is a little bit of a variation on what we've heard, so I just want to make sure I understand it. We're also aware that we might need to review this list because someone else has raised with us some other issues, so I don't want you to think I'm completely wedded to this list. I've got it under consideration. But we had thought of disability support organisations as offering individual advocacy and when you get to chapter 5, we talk about the DSO assisting a person in the assessment process to ensure that they get the best out of the arrangement. They maximise the benefits they would receive in terms of the outcomes they want to achieve.

So I just wanted to explore, if you don't mind, why advocacy services wouldn't be providing information about the scheme, why you would see a conflict of interest there. The advocacy service, why couldn't they be providing information about the scheme. Is that problematic in your mind?

MS BATH (PWDWA): They could provide information but if there was a complex issue and a conflict with the service provider that an individual was having, then that service provider could not advocate on their behalf.

MS SCOTT: No, I agree. If we have said that anywhere, we've clearly made a mistake, but here, we have been distinguishing between service providers, which is the dot above, and disability support organisations. We don't see disability support organisations providing, for example, attendant care; they would be service providers.

MS BATH (PWDWA): It does say in the report that service providers could act as disability support organisations for the services from B to F.

MS SCOTT: Yes, that's true, it does say that. If we make this clearer in the final report - and I just want to clarify this - if we had generic advocacy services separately funded, possibly separately funded by FaHSCIA, as many are funded now, and we had individual advocacy provided by disability support organisations and disability support organisations were not the same as specialist service providers, would that meet your concerns?

MR JEFFERSON (PWDWA): Did you envisage that disability service organisations would provide an individual to walk alongside everyone through the evaluation process, the assessment process?

MS SCOTT: I know that Mary-Anne mentioned in her presentation that she thought they should be walking beside everyone. I have to say I hadn't thought that it should be compulsory because there are highly competent people who, to be frank, I think might be offended if they thought they absolutely had to have someone walk them through the premises.

MR JEFFERSON (PWDWA): No, the intention was to be available to them.

MS SCOTT: I see, available. Look, I could live with "being available" but - - -

MR WALSH: I think we've made it clear in the report that it would be available and the intention certainly was that they would be independent of service providers. I take your point, Mary-Anne, that generic advocacy needs to be funded independently of the NDIS.

MS SCOTT: Does that sort of outline - maybe I'm being unfair to you, getting you to indicate a firm position. Maybe I could just say, does it at first blush suggest that we've heard what you're saying? So generic advocacy separately funded, individual advocacy available to anyone if they wish, and individual advocacy separate from specialist service providers, at first blush - not getting you to put all your resources on it but at first blush - does that look like we've listened to what your concerns are?

MR JEFFERSON (PWDWA): Yes, the concern, we have the advantage of providing both individual and systemic advocacy and one actually feeds the other really very well, so one informs the other.

MS SCOTT: Yes.

MR JEFFERSON (PWDWA): So could you envisage a situation - I hadn't imagined that an advocacy organisation would ever become a DSO. I would have seen them as being very separate roles.

MR WALSH: I think there's maybe some confusion about what we see as DSOs. I think we had thought that they, among other things, would be advocacy agents and this idea of them being aligned with service providers is not something that we had intended in the report. In fact I think it said that, Patricia.

MS SCOTT: It does, but just not exactly on page 31, which is unfortunate. It's hard to be consistent over 800 pages, done in a rush.

MR JEFFERSON (PWDWA): Would it be better to be non-committal at first blush?

MS SCOTT: I've decided that you don't want to be committal, so it's all right, fair enough. Mary-Anne, I interrupted your presentation. I'm sure there's other points you want to make.

MS BATH (PWDWA): We really wish to point out for WA that rural and remote communities are at an extreme disadvantage and a lot of people in WA are concerned that if everything is set up in the eastern states that WA is going to miss out and get the crumbs. How are rural and remote communities going to be served effectively considering people live in such diverse conditions, from north in the Kimberleys to south, down to Albany and Esperance?

MS SCOTT: Given that we're highly critical of the system as it serves many people in Australia, I think we certainly are not suggesting that anyone would ever get crumbs, Mary-Anne. We're suggesting that people would get their needs carefully and reasonably assessed. As in many locations, we've had people in Victoria talk about the times they have to travel because services are only located in Melbourne in terms of service delivery, so we're very conscious of this issue. There's nothing in the report I think that suggests anything other than people will get what they reasonably need. I don't even think there's anything in there about decision-makers being in the eastern states. I think it talks about the national system; maybe it's the way things are read sometimes. I'm pretty certain we don't even use the phrase "eastern states". We're thinking about the citizens of Australia getting what they need, reasonably.

We talk about regional offices. Now, you can have regional offices in Kununurra, in Broome, Esperance and Geraldton. I detect something in your presentation that I can't see in the draft report and I think it reflects in the misapprehension on your part.

MR WALSH: I think, Patricia, also there may be a misinterpretation in language. You said earlier in your testimony today that you preferred local area coordination over case management and I think this phrase "case management", while it appears in the report, I think it actually says "local case management" and that local case management is very much about understanding local needs and working with individuals and, where appropriate, disability support organisations to understand the individual needs. So I think, conceptually anyway, we should be satisfying what you're asking. As Patricia says, the regional decision-maker or the regional offices - a way to do that in regional and remote areas.

MS SCOTT: On the issue of what about service provision in these areas, this might be subject to criticism from other sources but we have acknowledged that, as is the case I think in WA, in some circumstances, it may be necessary for people to draw on their family to be paid carers, so we've suggested there be a trial to see if that is a way to go for some people. We talk about the fact that because people get individualised funding packages that they would be able to use people they're comfortable with to do their shopping; it doesn't exactly have to be HACC approved, going through the central agency person. They maybe do want to do that but we're suggesting that in some areas, neighbours may be willing to do that and people could use their individualised packages to support that.

We anticipate that in a system where funding is doubled that there will be more service providers, that people will have more choice, and that even in rural areas that people will have more choice and will not be forced to use the block-funded supply now. But I appreciate that if you go very remote it becomes very difficult. We went to Walgett in New South Wales, a fairly remote location, and there's some innovative work going on there where someone is providing a range of employment opportunities in a relatively small town - - -

MR JEFFERSON (PWDWA): Remote, rural areas. There seems to be, within our consultations, lots of talk about accountability. It's being talked about by people from within the disability sector, people who have knowledge of the sector, in a way that it sounds like they would be encouraging almost a limiting effect of that. Can that be countered in the way that the final report is drafted?

MS SCOTT: Andrew, I'm sorry, I don't think I'm getting your point. John, are you on Andrew's wavelength there?

MR WALSH: Andrew, if I interpret you correctly, are you suggesting that people are concerned that accountability might mean rationing?

MR JEFFERSON (PWDWA): No, I'm not concerned that - there seems to be a basis of mistrust in relation to individuals taking responsibility rather than moving toward, you know, "How can we support people to take that?"

MR WALSH: Yes. I think accountability in the context that it's used in the report is really about information. I think there's a great lack of information at the moment. I don't think we shy away from the fact that for a system like this, an entitlement system, to be sustainable there needs to be a lot more understanding of where the money is going than there is in the system at the moment where block funding in many cases is pretty invisible. So it's more about understanding - and it's also an opportunity for innovation. The more information there is around things that work well, the more opportunity there is to scale those innovative projects into other areas. So I think that's the context in which we use accountability. We can have a look at areas where it implies limiting in the report.

MR JEFFERSON (PWDWA): Thank you.

MR WALSH: Does that help you?

MR JEFFERSON (PWDWA): Yes, I think it does. I think it was fiscal accountability that people were becoming concerned about, and I felt that that was maybe the task of all this, to concern themselves with, that people with disability should be excited by the prospect for more decision-making and controlling their own destinies.

MS SCOTT: I think I'm agreeing with you Andrew, but chapter 6 might provide more comfort with people. We provide there on page 6.15 a summary of the impacts that international studies have suggested comes with self-directed funding. Remember, self-directed funding can be, "I love Perth Home Care Services and I want them to organise everything for me," while, "I would like to take my own package and organise it myself," to, "I like these five service providers, please send the money there and I'll indicate what I need them to me to provide."

But if we go to that page it ends up saying that the experience in the Netherlands and Canada and in the United Kingdom is that against a range of indicators people feel that they're more satisfied with the supports they received, they feel their individual needs are better met because somebody is responding to them, they're exercising choice, they've got better community interaction, the quality and confidence in the supports they receive has improved, they tend to be more independent, instance of abuse and neglect is reduced - so anyway, look, we've got quite a lot of material. We've also got an appendix that looks - a very lengthy appendix, I have to say. Ralph, is it up yet?

MR LATTIMORE: Yes, there's four.

MS SCOTT: There's four appendices. If you get a chance to talk to Ralph I'd encourage you. He's probably spent more weekends than anybody reading about self-directed care in a variety of settings.

What we heard from individuals, and I mean real self-directed care, I don't mean something that's called self-directed care but is in fact a form of block funding. We've spoken to a range of people. We even visited someone in their home just to see the paperwork involved and to talk to someone who had an intellectual disability and talk to them about their experience with self-directed care. We draw on that in the report about someone who used to get daycare services and really hated it, been there for ages and ages, and wanted to do something different. We explain that person's experience with self-directed care. I would have thought that people would - comfort by that.

Now, the paperwork does need to be minimised. We're very conscious that although you need to have accountability, people don't want to be overburdened. Some organisations will do the management for you. They exist, just as there are people who will look after - you know, conveyancers, there's markets that will exist with these things. So Andrew, I would encourage people if they have concerns to look at that particular chapter, and if they are good readers to look at Ralph's four appendices. Maybe they will take some comfort in that.

MR JEFFERSON (PWDWA): Thank you.

MS SCOTT: This woman, just by way of illustration, Fiona, she ditched daycare and the big bus that came along to pick her up and she went with public transport, training: public transport, movie every week, writing classes and art classes and had more involvement in the general community than ever before.

MS BATH (PWDWA): I think that some people reading your report wanted reassurance that there wasn't going to be a distinction made between, "This group of people with disability are able to manage their own funds but this group we should really look after and make sure that we apply different accountability standards," which is obviously not in the report but a concern for those with disability and their carers and families.

MS SCOTT: Okay. Maybe there's a way to reassure them on that. It's about everyone's unique circumstances. As you've said, I think we haven't made that point that people are worried about. A further thing may be to say is that in the UK - that we're often asked to look at - in some local government areas 40 per cent of people have taken up greater control of their arrangements. In other locations it's only 10 per cent. There's great variation in between. It seems to be how the confidence that we can instil in people about these arrangements, the confidence they have about exercising choice. If people can be confident that their funding is available and will be sustained then people will exercise choice and appear to enjoy the experience. But I have noted your point, Mary-Anne, so thank you for that.

MR WALSH: I think we also need to make the point, Patricia, that while we expect a small number of people to actually cash out their entitlements, that doesn't mean that everyone won't have control and choice. So we envisage that people will be able to - for example, the example of Fiona could still happen for anyone in the scheme. There's no distinguishing between those types of participants in the scheme.

MS BATH (PWDWA): Thank you.

MS SCOTT: Well, we're fast approaching time. Is there anything else you'd like to comment on or make a remark about?

MR JEFFERSON (PWDWA): We'll save that for our submission.

MS SCOTT: All right, well, thank you very much. Thank you for coming along today.

MS BATH (PWDWA): Thank you.

MS SCOTT: I now invite to the table Perth Home Care. Well, good afternoon. Thank you for coming along. We've got 30 minutes assigned to your presentation, and I'm sure you can anticipate questions. Please commence with an opening statement and just for the purposes of transcript you might identify yourself, please.

MS WALKER (PHCS): Marita Walker, chief executive officer.

MS YOUNG (PHCS): Melissa Young, manager of business development and marketing.

MS LAWN (PHCS): I'm Rosie Lawn, manager of community services for Perth Home Care Services.

MS SCOTT: Over to you, please, Marita.

MS WALKER (PHCS): It's my intention just to be very brief in terms of our remarks because they will be covered in our submission, but I want to firstly congratulate the Productivity Commission on the work that they have done. It's absolutely ground breaking and a major opportunity for people with disability and their families. So in terms of our response at this stage we want to acknowledge the things that we feel are very positive within the report, and probably keep that fairly brief because they're not things that you then want to change, and then speak briefly about specific feedback on or things that we feel could be approached in a different way or in more detail.

The first thing to say is that the fundamental reform is absolutely welcome. The move from their being a welfare payment that's pretty low down the priority to the funding for disability being legislated and second to defence is absolutely wonderful. If we can have this actually happen it will be a huge improvement on the situation that we have now, which we acknowledge when you look particularly at the situation across the country, could be described as dire or broken. So the fundamental reform is something that we absolutely welcome. The way in which that has been proposed that puts people with disabilities and their families absolutely at the centre in terms of power and choice and flexibility that is offered within the framework of the system is something that we strongly support.

The availability of certainty. I think that those can't be underestimated in terms of the importance for people, and knowing that it's not something that they will have to worry about next week and the next year. We very much then also support the focus on the system being person centred, having a range of options for people to have choice and control. That's an area that we feel that we have gained a lot of experience in in the last five to 10 years, about what that range is. Like the commission, we have heard a lot of anxiety from people over time about what it might mean, but for those people who we've been able to support to carry out to whatever level of involvement and choice that they wish to take they've grasped it with both hands. It is quite complex to talk about the spectrum that that represents.

It is very much the case that people quickly jump to the notion that they will have all their money, they will have a lot of responsibility for record-keeping and keeping track of the money and taking on employer responsibilities. I can understand that that's scary, because as a provider that can be pretty scary sometimes. But we know that that is just one end of the spectrum. There are lots of other points on that spectrum up to an organisation doing it on their behalf. We don't count block funding as the other end of that spectrum. It's about an agency acting on behalf of a person and their family. There's still a lot of choice and control that is possible to execute at that end of the spectrum.

I just want to reassure and make very positive comments about the strength of all of that within the Productivity Commission report, and that we have shared the sorts of anxieties that I know you will have heard and will for some time yet, but there are ways that people can - both from a system point of view, the providers, and the people in families can gain confidence and competence. There are ways that they can be supported to meet the technical responsibilities. The satisfaction about the - as you described within the international reports, we'd absolutely endorse those experiences.

So moving on now to some areas where we think that perhaps the final report might be able to be - more work might be done. The first one is an area where the report itself does ask for further feedback. That relates to the scope of people included, particularly when it relates to people who are experiencing mental illness. I really will strongly put the view of our organisation, which provides support both within the disability and the mental health sector, that people are people first, and that that's how we should see the framework for eligibility for the scheme that's proposed. If people have, from whatever cause and that is their - mental illness is the primary cause and they have an extent of disability that means that they require the types of support that are proposed to be within the scheme then they should be in the scope.

As it is with all sorts of physical, neurological or intellectual disabilities people have a very wide range of needs for support. As is very well described in the chapters about eligibility it's the extent and nature of the support that's required which should determine whether you're part of the scheme. So if it's a result of your mental illness, which maybe has a label of psychosis or schizophrenia but maybe it has some other label - but if the extent of your need for support means that you are unable to participate as a citizen or to live in your home in the community means that you need regular support to do that, then that's the criteria that we feel strongly means that you should be in the scope for the scheme; that as you've described in terms of a suite of assessment tools then it's just another part of the suite to determine the extent of the support required and the type of support that anybody else, whether they might have multiple sclerosis or a significant intellectual disability, does that mean that they're in?

So going on now to the role of state based disability systems and we're well aware that the level of anxiety and concern in Western Australia might well be higher than in a lot of other states. That relates to the feeling and experience that we have in WA of things that have been done, systems that have been set up here that are working reasonably well. So in terms of how good might that look in the future, there are a number of areas that we would recommend remain as functions that occur at a state level and are currently undertaken by the state Disability Services Commission. Where we've seen a lot of success there, in the past and with a lot of emphasis going forward, is about the work done to strategically influence state and local government in all those areas to do with health, education, transport, access in a broad sense as well as in the physical access sense, and at the state level where those things are controlled, that that's where those functions should remain and it's not something that sits well with a national system or national organisation.

Like other people have mentioned, we certainly see that the roles and the system of local area coordination has been a very positive and enduring and worthwhile system and although I don't agree with some people who have a perception that it's being swept away in what's proposed in this scheme, I think that there's ways that can be described in the final report that can better acknowledge what should be retained within that role. The previous people from People with Disabilities talked about case managers; local area coordinators strongly protest that they do that but it's mostly about the term, and they certainly do have a role of walking with individuals and families, guiding and facilitating them in terms of how they can gain most support, both from an informal community level and how to access supports that will best meet their needs from the disability service system.

So the role that the report requires for case managers, the functions are very much something that local area coordinators do carry out. They also are heavily involved in many of the functions that you have ascribed in the report to disability support organisations. We would be strongly advocating that rather than case managers, there be in WA consideration about the continuation of local area coordination. Whether it's used in that terminology, that's less important.

MR WALSH: Marita, before you go on, could I just ask you a question there. We have heard some testimony today about some of the shortcomings of the local area coordination process, not so much about local area coordination perhaps but about the allocation of funding packages to be able to opt into that. I guess what I'm asking is we're not interested in sweeping aside, as you say, anything that works, but are there things about the local area coordination process that could be improved?

MS WALKER (PHCS): Yes, nothing is perfect and there's always things that can be improved. I wasn't here earlier, but I wouldn't think that you can blame local area coordination for the lack of availability of funding packages.

MR WALSH: No, I wasn't suggesting that.

MS WALKER (PHCS): They're not the decision-makers, so they're not in the assessment process, as it's described in the proposed structure. Yes, of course it's not perfect, I wouldn't make that claim, but it combines both the number of functions that are described under the heading of Disability Support Organisations and I think does what you perhaps intend by what you call case managers, but I just feel strongly that "case managers" is a language that doesn't represent what it is that you are wanting to have as the fundamental basis of the system because people aren't cases and you want them to have choice and control, not be managed. That's perhaps more the point that I'm making.

MR WALSH: In the role as I guess walking with the person with the disability, are they able to act totally independently?

MS WALKER (PHCS): From whom? Independently from what?

MR WALSH: From the commission.

MS LAWN (PHCS): They do remain commission employees and I think that ultimately there would be some things - that maybe a local area coordinator is disappointed when a person applies for funding or there's a decision made that's beyond their control and for them, it puts them in a conflict of interest. I suppose we were also looking at your illustration of the roles. We probably would see that the local area coordination role here, it supports and sustains the family and the individual in the assessment process but they're not the actual assessors.

MS SCOTT: John, can I check if I've understood where you might be coming from. Are you saying - I just want to check - is it possible to take all the strengths of the local area coordination process as you see it and maybe even keeping that title and seeing that performed by what we have called a disability support organisation?

MR WALSH: That's right. We make quite a big deal about the disability support organisation needing to be an independent advocate almost. I guess that's where I was going with that question, yes.

MS WALKER (PHCS): I guess I don't have a strong view either way because it's the function as opposed to - I mean, as it is, it's being developed, it's being nurtured, it's being funded by a state disability system.

MR WALSH: And it seems to work.

MS WALKER (PHCS): Yes. So that's something we wouldn't want to lose as a functioning entity.

MR WALSH: Yes.

MS WALKER (PHCS): We can appreciate and understand that to achieve all the good things that relate to the doubling of funding of a system like this that the nature of that is an insurance scheme, that it's legislated through the national level and to achieve that outcome, you do need a national organisation. That's something for which the logic of that I can accept. One of the things that I'm going to be so bold as to suggest is that a national organisation, given the structure of what's been proposed in the report does borrow heavily from the things that have been achieved in WA, albeit still be things that are in development and could further improve. Then I'll be so bold to suggest that the national organisation might be based in WA, and that would overcome a lot of the concerns that people have about a national organisation - it's an assumption. We're very clear it's not what is written in the report. So I intend to make the suggestion that - - -

MS SCOTT: It's also not written in the report that it should be somewhere else either.

MS WALKER (PHCS): That's right, so I'll make a bid.

MS SCOTT: John, I don't know if you've got a view but I can't see a reason why it would have to be in Canberra, so it certainly could be in plenty of other places and I'm very taken with your weather here. So John, have you got any comment to make on that suggestion from Marita?

MR WALSH: We'll put your bid with the other bids, Marita.

MS WALKER (PHCS): I can understand that committal would not be where you could come from. The other point - we're moving on very quickly to our last two points in terms of implementation of the scheme - is that we can see that there's a huge amount of work to be done in implementation and a lot of the devil in the detail is something that people have anxieties about. The - have proposed that there be a trial in a region. We would want to strongly suggest that there isn't just one trial but there are trials in all jurisdictions. The report acknowledges that there are very different systems now, that there are good things in each of them; each of those jurisdictions, introduction of a new system starting from a different place. We strongly feel that there would need to be pilots in many jurisdictions; different lessons to be learned and then as a national organisation you'd want to be able to learn from all of them.

The other thing to say about implementation is that what we much applaud in terms of the emphasis on people themselves having choice and power is that does represent a huge cultural change. So we do acknowledge that in chapter 17 there's a list about all the things that need to be done. They are all valid. But the one key thing that's missing is that underlying all of that there is a large need for a cultural change and a very strong values base to underpin all the things that we feel so positive about in the report. Having experienced what that means for ourselves as an organisation we just want to emphasise to the Productivity Commission how significant that is and how it requires a very strong values base from wherever the organisation might be undertaking the change management. Also that it's about - values based, a lot of effort and quite a lot of resources.

We have had the privilege as an organisation to have some funding over the last four years from both FaHCSIA and from DSC which has enabled us to undertake the sort of learning journey and transformational change within our organisation. So we want to feel that that's the place we're coming from where we can acknowledge that for lots of other organisations and also that it's not just been us as an organisation but for people and families that they have needed opportunities to know what is possible, that if you have never had a choice then you don't necessarily know how to exercise it. If you've had very little power and you've taken what has been available then it's equally challenging to then just pick it up and run with it.

MS SCOTT: Point is well made, thank you. John, do you have questions?

MR WALSH: I think that's very thoughtful and useful testimony. I've just got your paper in front of me too. There are many, many things in there additional to what you've spoken about today which are also very useful, so thanks for that. Just on the mental health one, which you've talked a bit about, the intersection between community mental health and I think this goes to your point about the state infrastructure, the links between the disability system and the other state systems. How do you see community mental health crossing over with community-based support for disability? Are they the one thing? If they are, how do you deal with the medication issues with mental health and so on?

MS WALKER (PHCS): The medication issues are the easiest things because that's just the same as people with disability. A lot of this gets down to language. I will acknowledge that we are in a state where every jurisdiction has different language. So community mental health is very broad. It includes management, clinical management, of people and that would be outside of NDIS.

MR WALSH: That's my issue. So where are the borders?

MS WALKER (PHCS): I think the borders go back again to what are the types of support. So there's a range of support services within mental health that are very similar to the type of support services that there are within disability, so accommodation support, support for people who are needing assistance to link with their community. There are organisations like that in the same way as there are doing that for people with disability, and some of them overlap.

MS SCOTT: Marita, can I make a suggestion, that given that you actually are a service provider and I think you indicated right at the outset that you actually do provide services to people with psychosocial and psychiatric disability, could you talk about the services that your organisation provides, because it clearly must be the case that suddenly you think, "Wait a minute. This person might actually need clinical needs," and you obviously don't do that.

MS WALKER (PHCS):   No.

MS SCOTT: Could you just talk about your experience as a service provider? What do you provide to people that have got psychiatric disability?

MS WALKER (PHCS):   We're not a service provider doing accommodation support. We don't do any bricks and mortar things.

MS SCOTT: Right.

MS WALKER (PHCS):   So the support that we're doing is to people within their own home.

MS SCOTT: Yes.

MS WALKER (PHCS):   We are very focused on the philosophy of recovery. In many ways that's very parallel to people with disability who have issues that limit their capacity to involve living a good life, and in the same way people with mental illness. So the services that we are providing for some people are quite intermittent. They will have their clinical needs met by a mental health clinic, so that's not us, and that's clearly outside of what - that's just like a health service, basically. It just happens to be a community based mental health program. So we might be assisting them in many ways in the same way that we're assisting people with disability. It might be about maintaining their tenancy, so that the things that they need assistance with to ensure that their tenancy - and they still have a home; to be linking them with activities that they want to participate in the community so they're not isolated and prisoners within their own home.

MS LAWN (PHCS):   Interestingly we've probably learnt a lot with working across the two areas because we draw quite a lot around the thinking of individualised funding currently within the mental health area and we've been drawing quite heavily using a prototype of individualised funding with some of the people who have long-term mental illness who happen to be with us. It's very similar around having a strong person-centred approach, developing an action plan about a lifestyle and we're finding that there's a lot more that's similar than different. So, yes, it's like Marita says, every person, whether they have a disability, a mental health condition or are aged/frail, needs other specialised services but actually the functions about lifestyle, living well, is what's in common with them and having a strong individualised approach which is directed by themselves, so we're also putting quite a strong emphasis on self-direction which fits in well.

MR WALSH: Can I ask a very mundane question about if you do have someone who you've described and who might receive support, whether it be disability-type support or mental health or aged care - and I understand that it's all about the individual, not about the service - but how do you decide where the money comes from? So if we've got mental health in the disability system and you've got an individual support package that you're delivering, how do you decide how much of that comes from community mental health and how much of it comes from national disability insurance?

MS LAWN (PHCS): We have to track it all. Currently that's what we have to do at the moment.

MR WALSH: You do that, do you?

MS LAWN (PHCS): Yes. It certainly has considerable challenges and certainly old systems of service delivery around block funding means that there wasn't quite such amounts, but as you go down a self-directed approach, each person you support also wants to know where their money is going and we struggle with that still. I heard the analogy of a UK provider that if you're supplying supermarkets, you need juggernauts, whereas when you're providing in-home services tailored to an individual, you need a completely different financial and fleet system or something like that. So, yes, we certainly strive to do that, it's got some challenges, but I think that's where the future lies going down this track, that self-directed funding means that people need information around their funds and the supports they have received and an organisation needs to keep track of that and be able to provide that information in a timely manner to the person they're supporting.

MR WALSH: That's very helpful. We might come back to you on that one.

MS SCOTT: Yes, I think we will be.

MS WALKER (PHCS): That will be the case - for people to have choice about their services, even without taking responsibility for their funding, then organisations will need to do that because that's the level of question that people, if they're taking up the choice and power that we see the report encouraging them to do and we certainly endorse, then they will want to ask those sort of questions and organisations just need to start on the journey to be able to answer them.

MS SCOTT: That's right. Unfortunately I've got more questions than we've got time to allow but I guess that's the advantage of email, Marita. If it comes down to someone who has a physical disability, and while I appreciate it can improve or degenerate, they probably could be pretty predictable in their usage of, say, home services and their use of care or in their use of access to the community and so on, reasonably predictable. If someone has a psychotic disability, I imagine it's the case that they could feel really well but aren't actually very well. Their tendencies could be threatened because they're distracted and not thinking about eating and caring for themselves and caring for their home. So how do you cope with that situation? How do you know that this person who may not need your services for three months suddenly does need your services?

MS LAWN (PHCS): It's a lot about relationship, and I think ongoing. There's only a certain percentage of people with mental illness who - you know, there's a lot of people who have a mental illness who don't need disability support.

MS SCOTT: That's right.

MS LAWN (PHCS): There certainly is people - but I think with the fluctuations, there is a need for a relationship and that goes across all groups and I do think it does provide challenges for fluctuations but then the challenge means that the service system needs to be able to have the relationship and provide the support in the ways that the person needs at the time and a very strong interface with the health system. So this is about partnership working. If someone is unwell, they're unwell.

MS WALKER (PHCS): But you can set up some planning things before and reach agreement with the person, "What will be the actions that we'll agree that are to be taken if these are the signs that you acknowledge that you're becoming unwell?" So you can prearrange that. There isn't enough time now, but we can give you some examples about how that has occurred.

MS SCOTT: I particularly like the examples: a friend rings, a family member rings, they ring, the housing authority ring. That is what people have said to us, "How could you be confident that you wouldn't be overservicing someone, actually reducing their independence; on the other hand, that you wouldn't be underservicing someone, if it's of an episodic nature?"

MS LAWN (PHCS): That's an issue actually across disability services too, because it's very much often seen as a fixed theme. But you're right, it's higher with a person who has a more fluctuating condition.

MS WALKER (PHCS): I'm not sure if it's in one of the appendices that you have looked at, but Kevin Lewis, he is a UK expert - I can't remember his exact title - he has been in Perth recently and had some very good UK examples, where they are a bit further down the track with the mental health individualised funding.

MS SCOTT: Thank you for steering us to that. I have one last question. I'm sorry, I haven't got the figures at my fingertips; I know they're in my briefcase, but I don't want to dive into that and take another 15 minutes emptying it out. One of the features of the Western Australia state based arrangement - there are a number of strengths, and we acknowledge those and you have pointed to a number of them - but it is very rationed, much more rationed than in some other jurisdictions, to the point where we would envisage there would be a much larger group of people who would be receiving services; not necessarily large packages, they might well be quite small packages, but they would be receiving more supports. So here is a capacity question for you.

We have indicated in chapter 17 that we think that after a trial the scheme should be progressively rolled out, paying particular attention to certain groups. For example, you wouldn't deny someone early intervention because, "Wait a minute, it's not your year" - that would seem really ridiculous - and that you would address people who have been in the care of very elderly parents, that would seem to be an urgent need. Then we go on to say that we think the national rollout - sorry, I haven't mentioned dates, 2014 for trial, progressive rollout, full rollout 2018.

If you can imagine that there's a larger group of people in WA - you know, those people who often apply for packages and just miss out and are encouraged to apply again, or miss out because they didn't provide some necessary bit of information - and imagine that large numbers of those could actually be in a better-funded arrangement, what is the capacity of your organisation and the sector to adjust within the time period between now and 2018. I probably need to give you some sense of what the increase could be, but let's imagine it's - - -

MS WALKER (PHCS): I know the numbers of people who are currently missing out, in terms of the applications. 350 CAP applications that are unsuccessful.

MS LAWN (PHCS): Yes, and that's for people who have got to a CAP application - - -

MS WALKER (PHCS): Yes.

MS SCOTT: That's right, and I'm thinking it would be broader than that, because I'm talking about people who may have been so discouraged that they never apply.

MS LAWN (PHSC): Yes, that they just don't bother, right.

MS SCOTT: People who haven't got to the CAP application, because someone said, "You're not going to make it. Why bother?" Or people who think they have got to wait for a particular period of time, or they hit a certain age. So I'm talking about people who in a system would receive assistance. What is the capacity of your organisation and sector in WA to be able to grow to meet those needs?

MS WALKER (PHSC): Well, we have grown a lot in the last five years. We know what it feels like to take on too much, and we have gotten a bit smarter about doing that in a way that is manageable, and I think that all organisations can do that. I think the capacity issue is about recognising that it's not just going to be organisations in the specialist disability area; that's my other point about capacity. Yes, there will be more people and many will be still looking for what we might consider fairly traditional services, but I think - - -

MS LAWN (PHSC): It's not just a service response actually, is it? Interestingly, I was thinking that the capacity is being able to engage local, mainstream services, local people, is one of the things we overlook. So it will be a challenge. Meeting the demand is significant, and it will be about doing that properly, because you could put a whole lot of money into the system and not really get the right effect. Another thing is if you could nationally sort out some of the things that are barriers and the potential strengths around making it easy for people to self-direct, then that frees up a whole lot of resources for people who need more support, those who might not be able to engage their own supports. So I think there's some very clever ways around making things easier overall, which doesn't mean that there's just more and more support workers, or more and more managers.

MS SCOTT: I agree. That's a good point. Thank you very much for coming along today and for your very thoughtful presentation. John, we're going to take a break now for afternoon tea. Is that all right with you?

MS WALSH: Yes.

MS SCOTT: Good afternoon. I welcome NEDA to the table. We have allowed 30 minutes for your presentation. I'm sorry we're starting just a little bit later than expected. Just for the purpose of the transcript, could you state your name and then proceed with your statement. John, we have got something from Zel and Angelo, but we haven't been able to send it through to you. They were kind enough to give it to us just as they arrived. So I have got the benefit of some notes that you don't have.

MR WALSH: Thanks, Patricia. I have got the submission from last year.

MS SCOTT: All right, so, Angelo and Zel, begin when you're comfortable.

MR ISCEL (NEDA): Thank you very much. My name is Zel Iscel. I am the senior policy officer for the National Ethnic Disability Alliance, which we called NEDA for short. We did actually give a presentation last year as well. Thanks very much for having us back again. With me is Angelo Cianciosi. Angelo is NEDA's treasurer. We're going to be talking mainly about cultural competence today. Part of cultural competence is the need for language interpreters, the need for informal carers. We'd like to also bring your attention back to the issue of data in the culturally and linguistically diverse sector. Firstly, I'd like to hand over to Angelo to talk about cultural competence.

MR CIANCIOSI (NEDA): I can talk about past experience of working in the disability field. A great percentage of service providers come from an English background, there's not too many that would be from a non-English-speaking background. With the services that are provided for people with disabilities there's not a great deal of thought put into cultural differences; it's more on the person fitting in with what services are provided, instead of the other way around, instead of meeting the needs of that person.

I have an example that occurred about seven months ago, or maybe a little longer. The organisation that I worked for at that time had a Christmas mass for the service users from the organisation. But there was one particular guy whose parents are Jehovah's Witnesses and unfortunately there was a bit a clash with religious differences. We had to take him to a Catholic mass because of the way that service was structured for that particular day, but it was against his parents' wishes. The dad did not want his son to go to a Catholic church, but because of the shortage of staff it was like, "Well, he has to go," there were no ifs or buts. It was because of the staff that were rostered on that day; for him not to go would have meant a staff member staying at home with him, and the other staff member would have had to take the other three guys, it would have been a bit of a handful. So you can see where there's a bit of a problem with our cultural differences.

I just want to stress the point that at the moment with service providers we're not really dealing with the needs of people from a non-English-speaking background.

It could be because staff haven't got the expertise or the knowledge or even the people skills to deal with people from different backgrounds, but I think that is something that we have to look at in the future, to attract people from different cultural backgrounds; a lot of them these days are probably taking up different professions and are reluctant to get into the human services field.

MS SCOTT: Thanks, Angelo.

MR ISCEL (NEDA): Thanks, Angelo. What we say about that is that had this organisation to which Angelo was referring taken the chance to speak to the family and tell them the situation there could have been another arrangement made whereby the parents are satisfied and the organisation is satisfied as well. Because it was not discussed, there was some action that was taken that was against the parents' wishes. This is what we mean by cultural competence, for people to have enough awareness of how to deal with difference in the organisations with clients and so on.

So we thought we'd have a look at how culturally competent the system could be. The system needs to value diversity, needs to undertake regular cultural assessment, be aware of the dynamics involved when cultures interact, have institutionalised cultural knowledge, and adapt the service delivery so that it reflects the understanding of different cultures. Why we have so much emphasis on this is that the lack of cultural awareness, the lack of cultural competence, at the moment seems to have caused a lot of - well, there's a reportedly low uptake of services from people from non-English-speaking backgrounds and so on, and when I say "so on", I mean culturally diverse backgrounds. This can be traced to the lack of competence by the organisations. Firstly, the potential clients don't have confidence in the English language to be able to communicate or make contact with the organisation, but that's for those who actually know about the organisation. Many, especially those who come from countries where there are a very small degree of services for people with a disability, then they're not going to know that there are these services that are available that can help people with disabilities, education, they can help them with employment and so on. So in effect, a lot of these people with disabilities are actually not employed and not as well educated as they could be.

I was in the car with a taxi driver and he was an Iraqi refugee and he told me he had two daughters who were blind. I asked him whether they were working or studying and he said that they were actually just at home with their mum. So it is happening. There is another case too where we've had a woman from Afghanistan; she was told by one of the project workers at the place I was working at at the time - apparently she was also blind, this Afghani lady - and she had some issues with her husband and so on, domestic violence, I believe - and the project worker went to see this lady with another lady who knew the Afghani lady, and the Afghani lady would not open the door. Even though our staff is from a culturally competent background herself, the door just didn't open because the lady was afraid; she hadn't got permission from her husband to open the door - I suppose fear of the unknown. There was a lot she didn't know.

So with cases like that, you really need to give a lot of time for people to build their trust and to get them to be able to speak to you, so that will take a long time which is why we are actually pushing for multicultural advocacy. I believe a representative presented in Melbourne for the National Ethnic Disability Alliance and she did talk about multicultural advocacy. NEDA has done a study into the cost of how much advocacy would be to the country and I'm going to have to actually send you that information later because my computer is not allowing me to do too much at the moment, so I can't give you the direct figures.

MS SCOTT: Fair enough.

MS ISCEL (NEDA): But we did come up with a round figure that was an estimation of how much multicultural advocacy would be. What we actually said too is multicultural advocacy is present in some states and it's present in the big states, WA, New South Wales, Victoria, but it's very limited and in some cases there is just no multicultural advocacy. In states like Tasmania, territories like the Northern Territory and so on, there's very little representation of people with disability from non-English-speaking backgrounds. So we're saying that the multicultural advocacy should really be emphasised in those states where there is no other advocacy available for them.

What I can also tell you: earlier I touched on how clients or people with disabilities and their families don't have the confidence to approach organisations, service providers and supports because of their low English proficiency. So one of the other things that we at the National Ethnic Disability are pushing for is the costing of interpreters into services for the NDIS. So we're saying that it shouldn't be a part of the package where the people are using their package to fund their own interpreters but it should actually come as part of the NDIS. So we've costed that to the estimation there; we've got very limited information about how much interpreters are used and so on, but from what we could find, we came up with an estimation of $51 million a year for the cost of interpreters. That includes Auslan and Aboriginal languages as well.

MS SCOTT: Thank you. Can I just pause there for a minute, Zel. You hadn't heard some of the earlier discussion we had during the day where people were very worried that things would be coming out of the packages and that would diminish a package. If you have assessment based on reasonable need and someone needs an Auslan interpreter or someone needs someone to translate for them in particular circumstances where they can't use generic translation opportunities, provided that they actually got that, provided that was further to their package, why would it matter that it was part of the package? I think your anxieties and I think the anxiety of someone else I was talking to today is where you think it's the wheelchair or the Auslan and you don't get both, or it's the wheelchair or the translator. Can you imagine a situation where it could be that your needs are assessed and your reasonable needs are addressed and your reasonable need could include that you may well need a translation service also?

MS ISCEL (NEDA): If it's costed as a reasonable need, as you put it, then it shouldn't be an issue, except in cases where someone might need more interpretation and things like that. In that case, how would the packaging work? If you exceed the package, you may be left with a decision of, "Okay, do I find out more about a particular service or some services or do I just go with the services that I have because the money in my package for interpreters has run out and I can't find out any more?"

MS SCOTT: I guess this could apply to someone who gets a powered wheelchair and then finds the battery is faulty. We are anticipating that there won't be perfection in assessment processes and people will need to contact the NDIA to say, for these quite legitimate reasons, the package needs to be revised. So I imagine if someone had an intensive period where translation was required related to their disability services, they have got a legitimate need. I know why people are wary, because they have been so rationed in the past, but for you it doesn't really matter where the funding source is, provided the people get the services they need.

MS ISCEL (NEDA): Yes, that's true, and provided that there's quite a good level of cultural competence within the workforce. What I mean by that is not all agencies have access to interpreters at the moment but they have built in their own means of dealing with interpreter needs. So, for example, a lot of organisations hire people who speak more than one language. That can be quite effective because you could actually cut the interpreter costs by just using - an organisation can cut interpreter costs by just using someone within their own organisation.

MS SCOTT: Yes, that's right.

MS ISCEL (NEDA): Also, I guess I'm not against, and NEDA is not against, the provision of interpreters within the package so long as it's done wisely in that the more important consultations that a person does is actually covered by an interpreter but the less important information, I suppose such as finding out about - I can't think of a less important. But I would say the very important information that someone would need is what sort of services are available. Then if you want to be more specific about a particular service that could also be important but then if you have any further questions that are just additional to what you have already learnt then that would be considered - you might not need an interpreter for that. You could possibly get somebody from the community or your family to be able to help you with that. So yes, I do agree that it can be within a person's package, but it has to be managed well.

MS SCOTT: Okay, thank you for that. I note that in your written material to us you've given us some very interesting case studies, or a case study at least, I should say, of the Electoral Commission and its work on the Republic. That's very useful, because we do make reference, as you know, in the report to - if governments accept this proposal, well, accept the final report, one way or another that there would need to be information to the community and information to people who would be interested in accessing services and getting funding for services. So this example is quite telling, so thank you very much for providing that, it's very useful.

MS ISCEL (NEDA): Thank you. I just realised too I didn't have the costs in there but apparently it was only 8 per cent of the total budget that went towards the NESB information.

MS SCOTT: That's a good figure to have and, you know, the number of languages and the use of ethnic radio and so on. It's very good. Should we pause now and just see if John has got any questions?

MS ISCEL (NEDA): Sure.

MS SCOTT: John, do you have any questions for Angelo and Zel?

MR WALSH: No, as I said to someone else who attended this morning, the issue of people with non-English-speaking backgrounds with disability hasn't really been raised with us very much, so it's very useful to have this testimony. I guess one thing I was wondering, and it's really around the available workforce of people from non-English speaking backgrounds who may be able to make a cultural fit with people with disabilities, and I realise it's one of trying to juggle competing interests sometimes, but is that something that has been tried anywhere, to your knowledge?

MS ISCEL (NEDA): In New South Wales they have a system where - and I'm really not quite confident - I don't have enough knowledge of the system, but I can find out more - where they actually have people within the workforce, so within an organisation, can for a interpretation test, examination. If they pass the exam they can then also work to interpret information for people speaking that particular language. That, to me, sounds like quite a good idea.

MR WALSH: Yes, because right at the start you said that most care workers, I think, are from English backgrounds.

MS ISCEL (NEDA): Yes.

MR WALSH: I'm not sure that would be the case in New South Wales and maybe

Victoria. There's a very high proportion of support workers from non-English-speaking backgrounds.

MS ISCEL (NEDA):   Yes, that's very possible, actually. But I guess where there isn't a high proportion of people from non-English speaking backgrounds who are working as carers and matching with quite a high population of people from non-English-speaking backgrounds who are clients it becomes an issue because the clients aren't getting the services in the way that they need them to be provided.

MR WALSH: That's right. It may create even more problems if two people from non-English-speaking backgrounds who aren't culturally compatible - - -

MS ISCEL (NEDA):   Absolutely.

MR WALSH: It would cause major problems, I would imagine.

MS ISCEL (NEDA):   Yes.

MS SCOTT: Zel, you might be interested - I don't know if you've heard or have heard information about the New South Wales Care Careers campaign. I've heard and seen a number of the advertisements that the New South Wales government continues to fund, even though there has been a change in government, which are very much directed towards people who are not in the care sector now, paid care sector now, but who would like to join that sector. It's very much playing to the strength of people who are from culturally and linguistically diverse backgrounds because it's talking about the opportunities and the enrichment that you can both give to the person you're caring for but also the enrichment that you can receive from giving care. So it's called Care Careers and it's a campaign currently running in New South Wales. John, I don't know if you - I know you were involved in some of the earlier work in this area. They're quite compelling advertisements, I thought.

MR WALSH: Yes, it has been a very successful recruiting campaign.

MS SCOTT: All right.

MS ISCEL (NEDA):   Yes, it sounds very good.

MS SCOTT: Yes. Zel or Angelo, is there anything further you'd like to say? We should be thinking about wrapping up.

MS ISCEL (NEDA):   Yes. I'd just like to say a couple of other things that I'd like to stress following from our Sibylle Kaczorek's presentation in Melbourne. I just wanted to pick up on the issue of data, in that data is really - for people from non-English-speaking backgrounds who have a disability there seems to be a huge lack of data. I know we've said this before but I will say it again, only because there is a very big lack. The survey on disability and aged care, SDAC, used to only record the place of birth of a person, but that missed people who were actually born in Australia to parents who were born overseas. They've now changed that somewhat from the 2003 survey and they include languages spoken at home, which is better than what we had before but it's still not indicative of the cultural variations, including religion and the ethnicity and things like that, which can be very important if a person is living in supported accommodation, as we saw in Angelo's case.

Finally, I'd like to quickly make a point about the carers, informal carers, that I have in my notes. Again, Sibylle touched on this. Basically what I wanted to say is how the NDIS can work with this is to - we're calling for family members and friends to be permitted to work as employees for the person, so to work for the person and to get paid for caring for the person. Related to that is what we were saying about the carer visas, how the number of carers - the intake of carers has decreased in terms of migration. We're saying that the intake of carers should be increased. It actually should be part of the skilled migration visa.

MS SCOTT: This is because of the recent 457 changes. Is that what you're referring to?

MS ISCEL (NEDA): That's right, yes. How that works into the NDIS is that in that way you will be able to have more people from non-English-speaking backgrounds available in the disability workforce. Can I just also take John's point there. You did say that two people from non-English-speaking backgrounds from different backgrounds can also clash. That's true. I think that's why we definitely need cultural competence training that is ongoing and something that can be refreshed from time to time. Thank you.

MS SCOTT: All right, well, thank you very much, both of you coming along today.

MR CIANCIOSI (NEDA): Thank you.

MS SCOTT: Thank you for the notes and we look forward to getting your submissions, so thank you.

MS ISCEL (NEDA): We've sent it in.

MS SCOTT: You've already sent it in? Sorry, I've been on the road, Zel, for what seems like forever but it's only actually three weeks.

MS ISCEL (NEDA): Thank you.

MS SCOTT: Welcome to the table the National Mental Health Consumer and Carer Forum, please. Good afternoon.

MR FOWKE (NMHCCF): Good afternoon.

MS SCOTT: Now, we've assigned 30 minutes for your presentation but I'm sure you've been seeing, Tony, that we like to leave a little bit of time for questions and discussion.

MR FOWKE (NMHCCF): I hadn't actually planned 30 minutes anyway.

MS SCOTT: Good, all right. Now, for the record could you state your full name please and then commence with your statement. Thank you.

MR FOWKE (NMHCCF): Yes. My name is Tony Fowke and I'm here today on behalf of the National Mental Health Consumer and Carer Forum, the name probably explains itself, that it consists of mental health consumers and their carers, and also on behalf of ARAFMI, the Association of Relatives and Friends of the Mentally Ill. Both organisations are in the process of putting in a written submission, which I don't think you've received yet but they are both pretty well finalised.

Personally I am a mental health carer advocate, having had the experience of family members with mental illness, and in particular my son, who developed a mental illness and was receiving medical treatment and obviously decided that that treatment wasn't really enough for him, so he went on to substances and as a result had an overdose of substances that caused him brain damage. So he ended up in a wheelchair because it affected him physically. He still had his mental capabilities but he was in a wheelchair. He was in a housing corporation unit in Sydney. That was really the extent of how his disability was met. He did have a wheelchair which he got from some other organisation. So his actual support from disability was very limited and certainly he didn't receive any support for his psychiatric disability, which is what I'm really talking about today: psychiatric disability and psychosocial disability. So he was left to fend for himself. Unfortunately, again he decided that he needed something to help him do that and he took another overdose and died. So I come from that background.

I'm not sure how far you want me to go back because I believe there's been presentations on this before, but I always go back to the Convention of the Rights of Persons with Disabilities. In the preamble it recognises a lot of things but in particular says that:

> Disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in

> society on an equal basis with others.

There are many preambles. Another one is:

> The importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms.

MS SCOTT: Tony, because you have, as you said, earlier provided us with a submission in August, would it be more productive for your purposes if we asked you a few questions, because it's about operationalising this that we're finding it most challenging. Would that be okay?

MR FOWKE (NMHCCF):   By all means.

MS SCOTT: John, would you be comfortable with that?

MR WALSH: Sure, Patricia.

MS SCOTT: So, Tony, you can see that we're facing a conundrum in writing the draft report because pretty readily we came across a lot of people who said that there are things that are wrong with the health system, that are wrong with the education system, there are things that are wrong with the aged care sector - and it went on and on and on. Basically there's problems with everything and they all interface with people who have disabilities. In some ways they're sort of - I think the phrase that someone used today was sort of like a triple disability: the community doesn't provide - sectors, there's deficiencies in other sectors and people who are most vulnerable then find that they're triply burdened by all these factors interaction. So we resolved that no scheme would be feasible and affordable to the government if it encompassed an ambit which included everything, so we had to come up with an eligibility criteria. You can see we spent a lot of time trying to develop that.

It was the interface between the mental health sector and the disability sector that we found very difficult to draw a line. In some ways it was compounded by the fact that some people actually in the mental health sector said they don't want to be considered as having a disability, they've got a health issue but not a disability. So I know that you quite rightly have referred us to the UN preamble to the convention and so on. That's why we spent much time with Perth Home Care asking them questions about mental health. I've read the speeches by Hickey and by McGorry about how deficient they see the mental health sector. So here is the dilemma for us: there are a huge number of people in Australia that report as having a mental illness. At various times that may mean that they have difficulty with managing self care, but it may not be permanent. The people who are in a very under-resourced disability sector struggling with challenging behaviour and deficient resources have cautioned us that you make this too large it will be too expensive and won't get up.

So knowing that there are many people with depressive conditions and knowing that there is high incidents of people who self report as having a mental illness, where do you think is the right boundary between the mental health sector and community supports and the disability sector? Can you operationalise for us, because we can tell from your own experience that things aren't right and that without the right supports people end up with the most dreadful outcomes. But if we go for too much we might get nothing. Is that a reasonable characterisation, John, of the problem?

MR WALSH: Yes, absolutely.

MR FOWKE (NMHCCF): Okay, well, firstly, I think it needs to be said that not everyone with a psychiatric illness is disabled. There are people that live normal, whatever that means, lives with a psychiatric illness in the community and they certainly wouldn't want to be called disabled. So I think the important factor is the degree of disablement. Surely that's something that can be determined by experts as to what extent a person is disabled by their mental illness. It's those people, you might say the more severely ill people, that have this problem because there's really little they can do in the way of work, education, family life, all those kind of things.

My attention was drawn to the fact just the other day that there are people like that living in what are called psychiatric hospitals in Western Australia, and that's all they do. They just live in these hospitals. Is that a good life? We would say no. They are the people who have ongoing, persistent mental illness. We know that mental illness is episodic, so that's a difficulty in itself and when you have an episode you can be really unwell, but other times you can be quite well. So that's another difficulty in providing for those times when a person is really unwell. They have medical treatment. They may need other help as well. But I think from the determination point of view it's the degree of disability that's important.

MS SCOTT: Well, let's just go to that, because in the area of intellectual disability we ended up, even though we don't like using conditions and diagnosis as an indicator of need, because it's not a very reliable indicator. In the area of intellectual disability we did end up suggesting that be the criteria, because if you just go on functional need, daily supports - someone can walk and talk and shower themselves, manage their toileting and so on but when it comes to decision-making may flounder entirely. So that's why we, after consultation with groups of people with intellectual disabilities, included that condition. But I'm not too sure how you do a degree of disablement with people who have a psychosocial or a psychiatric disability and how you distinguish those from people who have a psychiatric illness. Are you aware of a particular tool that we can - you know, an assessment tool that we can use? Do you think I'm making it more complex than it is and that there's some reference that if we looked it up we would be able to exactly see how it works? Does it work well here in Western Australia, for example, with the new Mental Health Commission?

MR FOWKE (NMHCCF): I don't think so.

MS SCOTT: Okay, all right.

MR FOWKE (NMHCCF): Because that's where the issue of the people in psychiatric hospitals was raised. I'm not a medical person, you're right, and I've carefully not used any label for any mental illness, I've described it pretty generally because you can get impairment with any of those illnesses, although some of them are obviously worse than others. Ongoing illnesses like schizophrenia can be treatment resistant, for example, and so it's an ongoing problem which fluctuates. Those people need ongoing help probably for the remainder of their lives, so there are some people like that. There are others that respond to treatment and then don't need anything for awhile. Provided they adhere to the treatment things work out reasonably well. But decision-making is affected by the illness, self care is affected by the illness, eating, all the daily kind of things which you take for granted, they're affected, and the person's health suffers. It has been proven that they've got less life expectancy than the average population. That's part of the reason they don't get treated as a whole a person. It has been very silo orientated, I mean you've probably heard that before too.

MS SCOTT: We do want to break down the silos, because we're conscious of the poor outcomes that you get. But if you take it as all-embracing then it's all things to all people and then it's just phenomenally expensive. John, do you want to ask any questions of Tony?

MR WALSH: Yes, Tony, I don't know if you were there when Perth Home Care were presenting.

MR FOWKE (NMHCCF): I wasn't here, sorry.

MR WALSH: They have clients across the spectrum of mental illness, aged care and disability and they were talking about individualised support packages where that might cover a community mental health program plus a disability support need. They seemed to be able to apportion the funding according to which of those two needs is being met. Have you come across that or do you have any comments on that?

MR FOWKE (NMHCCF): I mean it has been in the disability field for some while and the Mental Health Commission are proposing to have a similar model for psychiatric illness, that's in Western Australia, but it's still not clear how it's going to work. I really have difficulty in imagining how it's going to work, how you'll apportion that money over the whole area, how much you give for the medical side and how much for the social side and housing and all those kinds of things, because unfortunately it's not a stable environment. People with intellectual disability are fairly stable in many respects, whereas with psychiatric illness you don't get the same thing, so the needs change well daily, hourly, whatever it may be. It's an interesting concept but I am still not clear in my mind how it's going to work.

MR WALSH: Yes, okay.

MR FOWKE (NMHCCF):   It's going to be experimented, obviously, first and then take it from there.

MS SCOTT: Well, we will have the benefit of meeting with the Mental Health Commission, so we'll have a chance to ask them those questions. Well, I still feel that we've got some glimmer of hope because we've heard that people are able to operationalise it, so that will mean that we can pursue this a bit further with some of the providers. Tony, is there anything else that you would like to address in the remaining time available, any further points you would like to make?

MR FOWKE (NMHCCF):   I don't think so. I think you've had the paper and the further paper has come in.

MS SCOTT: Thank you.

MR FOWKE (NMHCCF):   I don't think there's very much I can add except that on the Productivity inquiry for aged care I was involved in that because there's obviously an interface there too. People with psychiatric illness get older, but possibly not - they don't live as long as the average population but they get to the stage where they need aged care. So there's an interface there too because they may need the disability and they may need the aged care.

MS SCOTT: Yes.

MR WALSH: Tony, can you talk a little bit - sorry to throw this in at the last minute - about what the support needs of someone with a psychosocial disability might look like? We've heard community support, we've heard people have difficulty leaving their homes, relationships. What sorts of supports might assist to overcome these difficulties?

MR FOWKE (NMHCCF):   Well, I think a lot of the support would be making sure the person cares for themself to the best ability but taking them shopping, taking them to the doctor, all those kind of routine things that they can't face doing themselves. It's something like the PHaMs - you've probably heard of the PHaMs

FaHCSIA thing?

MS SCOTT: Yes.

MR FOWKE (NMHCCF): Where people get help from people to take them shopping trips or whatever it may be. So all those things, routine-type things, you may think, that we take for granted that they can't do. They're either not motivated or lose the ability to do them which are essential parts of life.

MR WALSH: Those sort of personal support episodes, help, do they need to happen on a daily basis or once a week? What sort of support is needed to help someone to start to interact with the community?

MR FOWKE (NMHCCF): It depends upon the individual. In the case of my son when he lived in Sydney, it wasn't easy, and he certainly never got any housework done, and that was one of my tasks when I went to see him, to clean up the place. You can't really leave it for six weeks before you do something like that. Even the washing up, dishwashing, washing, clothes, all those things that just become too much, so it becomes an unhealthy environment.

MR WALSH: Yes. Patricia, I am still struggling with this one, pretty much.

MR FOWKE (NMHCCF): With the national disability strategy, hopefully that's going to deal with some of the issues that are raised, and providing psychiatric disabilities are included in this, then that's the way forward.

MR WALSH: Yes.

MS SCOTT: Thank you very much for coming along today and for your testimony.

MR FOWKE (NMHCCF): Thank you.

MS SCOTT: I now invite UnitingCare West to come forward, please.

MS TILLEY (UCW): We're part of the mission of the Uniting Church and the UnitingCare Australia network. We deliver services to about 30,000 Western Australians every year and we provide a broad range of community services. So in addition to the mental health and disability services, we also provide accommodation support, services for families, for children, for youth, for individuals who are homeless, for people who are impacted by the justice system, on exit from prison and a whole range of other services and supports to the community. We're particularly focused on those most in need and we seek to support, serve and empower them to create justice, hope and opportunity for all.

Now, in terms of the Productivity Commission's report, there's a number of statements that I would like to make in relation to that and then if it's appropriate, to address some critical issues that are of interest to our organisation. The first thing that I'd like to say is that UnitingCare West supports the implementation of a national disability insurance scheme and, broadly speaking, the proposals that are put forward in the Productivity Commission's report we like. We support the idea of a national scheme that's coordinated. We were impressed with the way that the commission had listened to the voice of the consumer and families about what's actually needed and about what's not working in the system.

We like the element of choice, the commitment to certainty for families and for individuals experiencing disability and we support the notion of the funding for the schemes coming from consolidated revenue and the processes described there. We think that it's very good that there's been recognition that it's not okay in Australia to put people through demoralising and dehumanising systems in order to access critical supports. We think that it's not okay for geography or for the cause of a particular disability to determine what you can and can't access. We agree with the proposition that's been put in the report that current services are in a death spiral and that it isn't just about more money going into the existing system which focuses very strongly on rationing and has a very narrow focus of disability and that was one of the very encouraging ideas that we saw coming through the report. However, we are conscious that potentially the devil might be in the detail in terms of what's included in the report.

So we identified six critical issues that we think need to be addressed or considered further in terms of moving forward. The first one is about access and support for those individuals who are multiply disadvantaged. There is some consideration of this in terms of the references to indigenous Australians and we particularly support that. However, we would also like to ensure that the commission is mindful of other groups of Australians that also experience multiple disadvantage. So there are many individuals with disabilities who have other significant barriers such as substance abuse, poverty, homelessness, broad sort of social marginalisation or concomitant disabilities; mental health is one in particular, and I'll also talk some more about that in a moment.

Many of these individuals are excluded from the current systems and current services. They are either unable to access because they lack some of the basic kinds of criteria that accessing many bureaucratic systems requires. They may not have a home, they may not have a phone or an address - they have real difficulty actually getting into services - or the eligibility criteria of services focus on exclusion. So the look for reasons as to why individuals might not be suitable for a service rather than looking for reasons as to why an individual needs a service and we see lots of sort of buck passing in terms of, "It's the substance abuse problem, it's the homelessness problem," it's all sorts of other problems, whereas in fact many of these individuals present with all of these issues.

Many of these individuals as well don't necessarily see themselves as fitting easily into the current disability system. Not all individuals with disabilities, which is very much acknowledged by the report, are born with their disabilities. For a number of these individuals, for example, those with an acquired brain injury, those with a disability as a result of severe mental health impacts or as a result of significant substance abuse, fall between the cracks of the existing services. They are different. They often have life experiences. They often have some basic skills in literacy and numeracy. They often have an understanding of what it is that they're being excluded from, but they don't have the capacity at this time to access it. We do need to think about the types of services that we provide to these individuals because they don't necessarily fit traditional services. They often though will need access to early intervention or access to services that are able to meet their individual needs because these are often the individuals that are very confronting in terms of the ability of our society to provide support for them. So one of the things that we would like to very much see in the new system is some more information about how the NDIS will address the needs of this population with multiple disadvantage and ensure that it actually identifies and addresses their needs.

One of the other things that I think is significant and which we struggle to look at in terms of the new proposal is they often will need access to early intervention or access to services that are able to meet their individual needs because these are often the individuals that are very confronting in terms of the ability of our society to provide support for them. So one of the things that we would like to very much see in the new system is some more information about how the NDIS will address this population with multiple disadvantage and ensure that it actually identifies and addresses their needs.

One of the other things that I think is significant and which we struggle to look at in terms of the new proposal is in some instances there's recommendations around referral to existing services. One of the big challenges that service providers and individuals with disabilities have is a lack of existing services and a lack of available infrastructure. Case management is only useful if there is somewhere to refer individuals to.

The second issue that we wanted to raise was with regards to classification, assessment and eligibility issues around the proposed system. We understand the need to be focused on those individuals with significant disabilities, but we were very unclear about what happens to those individuals who might fall just outside of that definition of significant disability. That is going to be critical, in terms of the success of the system, and we think there needs to be some further consideration around what happens to those individuals who have moderate disabilities. Where do they go? What sorts of services are going to be available for them? Is it the existing services? Is it new services? How do we ensure that we don't create a new class of individuals who are also not having their needs met and are still struggling within our society?

In particular, a number of these individuals also interface more with a range of the other mainstream services. So these will be some of the individuals perhaps with a mild disability, of whom we have significant numbers in the justice system; it will be individuals who have mental health issues and homelessness issues and who interface with the health system. How we address those sorts of requirements needs to be considered.

Within the classification and assessment processes that are undertaken there is a real need to avoid lengthy time and significant expenditure spent on those assessment and eligibility and allocation processes. So there needs to be a real focus - and this is something that comes through in the report - on assessment processes that are simple, that focus on strengths and not on deficits; and that can be a challenge when you're allocating resources, but we think it's important in terms of the hope and the focus on addressing people's needs for the future.

We also think skilled, trained assessors are needed who care about people and are focused on outcomes for the hours or the dollars that might be made available. It will potentially ensure that we don't fall into systems of substandard care that are operating outside of existing legislative requirements for occupation health and safety requirements or insurance requirements. We have seen examples of where some of the systems that have been put in place in terms of individualised funding may have resulted in potentially difficult situations, where vulnerable people may not perhaps have been appropriately supported because there hasn't been enough consideration about the cost of care and the factors that are also required in order to ensure that that care is of a quality and standard that is acceptable in our society.

The third issue that needs to be considered - and I have touched on this one already - is mental illness. We think that determination of who provides the supports and how those supports are determined will be critical. We do believe that people with a disability as a result of a mental illness should be included, and in fact must be included in a national disability insurance scheme. There's lots of clear determination within the report around some of the challenges between the aged care system and the disability system, but there's not a lot of detail around the mental health system - and I note that that's one of the areas where the commission has asked for additional input - and I think that will be critical in order to have a successful system that supports the needs of all.

Some of the proposals about sharing responsibility for care and support with the mental health system need to be spelt out more clearly. I think that there's a danger that some of those may end up veering away from the principle that is clearly there in the rest of the report, about support being provided regardless of cause and about focusing on the level of impact or the level of hardship for an individual with a disability. Certainly, individuals with a mental illness frequently present with significant functional disabilities as a result of their mental health issues. Support for individuals - through the NDIS - with a mental illness, we believe, should be focused on support in the community and enabling individuals to continue to live in the community or to receive the support they need in the community. Support also needs to be recovery-orientated for individuals with a mental illness.

In terms of the needs of people with a mental illness, they need very much the same kinds of support that individuals with a range of other disabilities need. They have personal care needs, often on a daily basis, and they require community access support, domestic assistance, transport assistance, therapies, case management, respite, and crisis and emergency supports. I believe clinical care should still be delivered by the mental health system, and in many ways I see it as being equivalent to the kinds of physical care needs that a person with a disability may have - for example, in terms of accessing their GP, accessing the hospital. We felt that was perhaps a useful analogy in terms of how to make the distinctions between those.

With regards to case management for individuals with a mental illness - and there was some discussion around how that might best be provided within the document - we felt that there needs to be a single point of contact across both systems and that integration of the systems is going to be critical for the success of this right across the board. There are some examples from the COAG care coordination trials; some examples of very good practice, also some examples of poor practice. We think that that will provide some evidence and useful data for the commission.

It is important though that case management is funded and is seen as an integral part of the system. It is also important that case management is flexible and is able to respond to the needs of individuals. There were some comments in the document around six-monthly visits and links to case management. I was unsure whether that was around case management in terms of determination of eligibility or whether that was case management in terms of the ongoing support and management of the individual.

MS SCOTT: The second one.

MS TILLEY (UCW): Okay. Six-monthly visits would in some instances be very problematic particularly for clients and families who may be very disorientated, very distressed, very anxious and really struggling. I think that may be different perhaps once we have a system that's in place and that has been functioning for a while, but certainly initially that timeline could be problematic. The next area that we identified was around standard setting and quality systems. This is critically important and needs more detail and more development around what that would look like, and again we have some queries about how feasible this is, and I'll come back to the time frames towards the end.

We agree with the development of national standards, but know that that will take time. There's some comment and commitment around state and national accreditation, but not a lot of detail about how that might be developed, and we believe that that's an area where we can potentially work together across the sector and look at ways and means. We think there's potentially some need particularly for the non-government and not-for-profit sector to become more sophisticated and look at some processes around self-monitoring and some standards and accreditation that might be appropriate there, looking at things like codes of practice across the sector, those kinds of ideas. But they're very new and would need some further development, in terms of how that might be achieved.

We agree and support the notion of outcomes being what we want to measure in the new system, but we are also conscious that this has proved to be a very challenging process. I would suspect that there are a number of organisations who have contracts that say that they will be measured on outcomes; but we haven't yet figured that out, so we're just going to stick to outputs for the moments. Many of the challenges are around things like the sorts of population and demographic shifts which you are often wanting to measure in terms of outcomes, but we believe there are some mechanisms that could be put in place around outcomes for individuals that can then be amalgamated to look at broader outcomes there.

We think that there's some issues around the role of small, grass-roots, not-for-profit organisations. They can be very strong providers of services, and we have some very good examples of those already within the not-for-profit sector. In terms of being very client-focused and providing choice, they are very good and have some real strengths in those areas. But we are also very aware that many of them can struggle in terms of sustainability and capacity, and I think that is another issue that needs to be explored in more detail, to look at how the NDIS might function within that kind of environment. We absolutely agree that we need to avoid or adequately fund for the potential compliance burden, in terms of reporting and achievement there.

Another factor we think needs to be considered is the suggestion in the report that who supplies the service and the ownership of the service is not of significance to the implementation of the NDIS. We would sound a note of caution with regards to that and suggest that perhaps the experience that Australia had with the ABC Child Care Centres needs to be taken into consideration when we look at full profits, moving into an area which is very value-driven and requires a commitment to individuals and not being driven by a profit based mentality. So we would suggest that ownership is important and can have an impact on the sustainability of the services. That is really important, from our experience, for people with disabilities and their families. Again I will come back to the timeline, for all of the work that needs to be pulled together, in terms of this.

MS SCOTT: I am starting to feel exhausted, Fran.

MS TILLEY (UCW): I have got two more, sorry, Patricia. Can I finish them, or would you like to ask some questions in between?

MS SCOTT: I know, I have got a thousand questions. If you could quickly go to time frames, that would be good because effectively you have set John and I - and, I have to say, an extremely small team - a very large set of heroic hurdles to jump. So I'm hoping that any second now you're going to tell me how UnitingCare West is going to help us out on this.

MS TILLEY (UCW): We are certainly very happy to work with you to look at how we might address these things, and we also have that broader UnitingCare network to look at supporting the processes there as well. The fifth area - which I won't go into - is the workforce shortages. We do think there needs to be again some consideration about some of those, and some of the suggestions that we think have been made in that area may in fact have some negative implications, in terms of whether we're focusing on the needs of clients or the needs of workforce and the potential tensions between those two areas and just the importance of getting them right.

The last area was around the time frames and we do think that the establishment and the implementation timelines are very tight. We think you have set yourself a very large piece of work to be able to undertake. Particularly because there's talk about the need for the present arrangements to stay in place while we start the process of rolling out in a small way and then looking at a larger rollout, I think we need to be very careful about the possibility of white-anting while we have two systems running, because I think that there is potentially a perception that if more money was given to the existing system everything would be all right.

However, that is not our perspective. We believe that the commission has got it right, in terms of talking about the fact that we actually need a new system, that the existing system just doesn't need more money thrown at it in order to prop it up, that there are some fundamental issues around the determination of who receives support, how that support is delivered and the sustainability of the existing system. So that would be one of the reasons why we think that time frame and implementation is really important.

We just looked at the range of things around IT, data infrastructure, the new standards and new quality systems; there's a lot of work, in terms of supporting some of the issues around risk-management, implementation of electronic record systems, all of those sort of factors. It's not that you haven't identified that they're issues that need to be addressed, but it's just within a very short time frame, and I wouldn't like to see the system undermined by that.

MS SCOTT: John, are you comfortable if I lead off this time?

MR WALSH: Yes, sure, Patricia.

MS SCOTT: Fran, I don't think there was much you said that I didn't think would be very worthwhile us answering. I just realistically wonder how we're going to do that without organisations such as yours, not just telling us there's an issue here but actually suggesting the solution. For example, if you think the time frame is ambitious, then please indicate the time frame you think we should be considering. If you think that small grass-roots organisations are fantastic but they may not be sustainable, well, we'd probably agree, but then what is your solution to that.

In terms of every one of the issues you have suggested - for example, what happens to people with moderate disabilities; well, that's a good question and we'd be happy to go to that - it's actually more important that you provide us with the answers than that you provide us with the questions. That's the challenge that I'm suggesting for you. You have got the fantastic experience of actually operating in the sector in such very broad areas, you can see the operational issues on a daily basis; something that I'm never going to be able to have.

Therefore what I actually need, for each of those issues you raised, the six critical issues, are your answers to them. For example, let's take something easier, like people with multiple disadvantage. What are you suggesting that John and I consider when someone doesn't have a home, a phone, a stable address, may not see themself as disabled? What sort of services do you think the NDIA should be offering to that person?

MS TILLEY (UCW): I think that it's probably about the way that we link and support those individuals to be able to access the support that the NDIA can potentially provide, and part of that is about utilising organisations such as UnitingCare West and other organisations similar to us, because we do already have those established links. We are very happy to work with the NDIA and look at ways and means that we can potentially link those individuals in and look at ways that they may then be able to access exactly the kinds of services that the NDIA is talking about providing.

Where there will be difficulty is if that system of access is set up so that it inadvertently excludes those people further, and some of that will be around some of those tensions around providers being able to support individuals into access. So we can certainly provide information and contact through our services, because these individuals already come to our services.-

MS SCOTT: That's right.

MS TILLEY (UCW): So access can be achieved if the NDIA is willing to allow us to enable that to be part of how the process goes.

MS SCOTT: Here is a trickier question then. If you're the interface for those services and you're currently funded to do that work, should we be looking at the funding you currently receive and thinking of it as coming into the bundle, or do you see those services best provided by the NDIS having a memorandum of understanding with your organisation and you continuing to get funding; for example, I imagine, under whatever the SAAP program is currently called?

MS TILLEY (UCW): I think that there might even need to be both sorts of approaches.

MS SCOTT: There may well be.

MS TILLEY (UCW): Yes, because I think that certainly there may be some of those individuals who could be better serviced by an NDIS, or through the NDIA; but I think there will be some of those individuals who will still need to sit in those existing kinds of programs and resourcing and servicing. Bear in mind too that we don't provide all of these services with government funding.

MS SCOTT: No, that's true. I acknowledge that. John and I aren't interested in totally crowding out the not-for-profit sector from their very good work. One of the issues we have talked about is the fact that under the current arrangements a lot of activity goes into fundraising for the wheelchair, whereas we think in a wealthy economy and society that really should be the function of government, and community organisations could be handling some of the most difficult issues, in terms of community access and engagement and community support.

Maybe I should leave my comments there, except to maybe just once more reinforce that I didn't have any trouble with the issues, I am just hoping that when we get your submission I can see the issue and then I can see your solution. So that we can look at that and think, "Fantastic, let's use that in the report." We find the use of examples very telling. You have obviously got lots of experience to draw on, we would welcome that. John, do you have some questions or comments for Fran?

MR WALSH: I have a few, Fran. The first one goes to your comment that you don't just rely on government funding. I think I just reiterate Patricia's point that far from sort of suggesting that you stop raising money from other sources I think this whole issue of community capacity will require organisations like yours to continue to engage with the community in building that capacity.

MS TILLEY (UCW):   Absolutely, John. That's a fundamental part of our mission, is to in fact do that. I suppose my comment in that sense was really about sort of identifying that particularly sometimes if the information about need is coming primarily from government and they're basing it on funded services it's really important to recognise that there is this bigger, broader need that isn't necessarily addressed but is picked up by organisations because they're there at the coalface, you know, seeing the need and responding to it.

MS SCOTT: That's right.

MR WALSH: I've got two more, Patricia. The first one is about implementation. Fran, I take your point that it's an ambitious time frame. Other people are saying to us, "We can't wait that long. We can't wait till 2018." So you're telling us how hard it is to get it in by that time frame, you might also tell us how we can do it quicker to satisfy those people. My last one is around your comment on - I think it was your second-last critical issue, which is around tension between thinking about the needs of the people with disability and the potentially conflicting needs of the workforce. Just for the record I wouldn't mind you just to expand on that a little bit, please?

MS TILLEY (UCW):   Yes. One of the examples that was talked about in that area of workforce shortages was that there were some specific kinds of activities that organisations might be able to undertake in order to attract workforce. It talked about things such as - and I'll just have a look at my notes so I can recall exactly what they were. Things like shorter shifts and longer breaks between shifts. One of the issues sometimes around - that we certainly - and then it also referred to potential productivity increases that might be implemented around things: they've talked about bed-turners and electronic alarms as being two examples of the sorts of productivity increases that might be able to be achieved.

One of the things from our experience of delivering services to people with disabilities - and again, this has been commented on significantly by the report - is the importance of the personalisation of it and the importance of the relationship between the individual providing the care and support and the individual with the disability. Some of the impacts of things like shorter shifts and longer breaks between shifts can run the risk of potentially resulting in more institutionalised practices. So if I give an example from a group home situation. We run a number of group homes that provide support to individuals with significant intellectual disabilities who rely on routine and knowing about what is happening and rely on the relationships that they have with individuals to provide them with a safe environment that they feel comfortable with.

One of the things that our individuals that we have supported have let us know is that something that is really important to them is that when they go to bed at night whoever it is who is there when they go to bed at night - it's really important that when they wake up in the morning that the same person is there, and that it hasn't kind of - something magic hasn't sort of happened in the night and Mary was there at 10 o'clock when they went to bed but when they get up at 7 o'clock in the morning Mary is not there at all. That can directly conflict with some of the ideas around shorter shifts and longer breaks, because we structure our rosters, for example, so that the same person is there at night when someone goes to bed as is there in the morning. But there are significant industrial issues, potentially, with that, the whole issues around sleep shifts and length of shifts and those sorts of things. That's where we see some of the tensions between the kinds of care that individuals might like and some of those kinds of impacts.

Similarly with some of the ideas around bed-turners and electronic alarms, that just set off some issues for us around institutionalisation and some of the impacts of effective work practices. They might save time and money but they can actually very quickly lead you down a very conformist, everyone must behave in the same way kind of outcome. I think from my own experience in my very early days of working in institutions where you could very quickly give everybody a cup of tea because everybody had their tea white with two sugars and it was made in one enormous pot. Literally the staff would walk around the wards and tip out that kind of tea. If you didn't happen to like your tea white with two sugars, well, too bad, because it was a really efficient way of providing that service. I just think we need to be really careful. We very much focus on in those settings - we are providing a home for individuals. Choice and control about what goes on in that home is critical, whether it be how you have your cup of tea or what kind of system supports you as an individual or who it is who provides that care for you.

MR WALSH: Yes, thank you. The main message in our report is choice, so I don't think we are going there, but thanks for the point.

MS TILLEY (UCW): I don't think you are either, but the examples might potentially have led some services in that direction.

MR WALSH: Thanks, Patricia.

MS SCOTT: Thank you very much, Fran, for coming along. I look forward to getting your submission.

MS TILLEY (UCW): Thank you.

MS SCOTT: Now, we've got Karen Miller, who is going to talk to us briefly. Thanks for coming along, Karen.

MS MILLER (CORDS): Thank you.

MS SCOTT: So I think you're representing an organisation, so just for the record do you want to say who you're representing and then just lead off.

MS MILLER (CORDS): Sure.

MS SCOTT: John, we might hold our questions till the end just so Karen can get through this material and then we'll see how we go.

MS MILLER (CORDS): Thank you. Thank you for the opportunity to speak today. It is our intention to submit a submission but it's a work in progress between nine organisations, so I thought we'd just present the basics today. So my name is Karen Miller. I'm the CEO of the Wheatbelt Individual and Family Support Association but I'm here today as a representative of CORDS, which is the Council of Regional Disability Services. CORDS members are made up of, as I said, nine organisations: we have Access Ability in the upper great southern, based in Narrogin; Advocacy South West based in Bunbury; Enable Southwest in Bunbury; Goldfields Individual and Family Support Association in Kalgoorlie; Kimberley Individual and Family Support Association based in Broome but covering Kimberley and Pilbara; Lower Great Southern Community Living Association in Albany; Lower Great Southern Family Support Association in Albany; Strive Warren Blackwood region based in Bridgetown; and the Wheatbelt Individual and Family Support Association based in York.

The CORDS group, the Council of Regional Disability Services, was established in 2004 to provide a forum for people in leadership roles in regionally governed disability services to share information and discuss common problems. This allowed the executives of those organisations support from their peers and greatly reduced the isolation experienced due to distance. All members of CORDS are organisations that are governed by a board drawn mostly from the local community where the organisation is based, are DSC funded and not for profit.

CORDS strongly support the need for changes in disability care and support. We acknowledge that Western Australia has a solid base of support to people with disability with a functional and responsive Disability Services Commission, state-wide service coordination and local area coordination systems. CORDS consider that parts of the existing system should be retained when reforms are considered. There's a belief in WA that the current service system is not broken, yet we have people waiting between one and nine years for funding in the combined applications process, 35 per cent of people more than three years and between 86 and

90 per cent of applicants are rejected at each funding round.

MS SCOTT: Okay. Having said I'm not going to interrupt you, I am. Can I just get those figures down.

MS MILLER (CORDS): Sorry, yes. They're taken from NDS WA's pre-budget submission this year.

MS SCOTT: Thank you.

MS MILLER (CORDS): That was between one and nine years waiting for funding in the CAPS process; 35 per cent of people wait more than three years, and between 86 and 90 per cent of applicants are rejected each funding round. Funding is still delivered via programs that compartmentalise people's lives and support needs.

The Productivity Commission draft report proposes an entitlement scheme. Any scheme that removes the requirement for people to paint the worst possible picture and expose their lives bare to others to receive any support is a step in the right direction. Further, people should not have to compete with others in similar situations, pitted against each other in the process of securing the support they need to maintain a quality of life in their own homes and communities. Disability support should be an entitlement. The current scheme is unfair, underfunded and inequitable, particularly for people with disabilities, their carers and families living in regional, rural and remote areas, and CORDS intends responding to those areas and recommendations affecting regional issues. My apologies if I state anything that's already been addressed today.

MS SCOTT: No, that's fine.

MS MILLER (CORDS): This paper was prepared earlier. Where possible, regionally governed disability services should remain the foundation of the regional disability service sector as they provide a valuable resource for people with a disability and local communities and to the foundation of good regional solutions. Many innovative programs have arisen from regionally governed disability organisations, finding local solutions to issues and working in collaboration with local communities. CORDS urges the Productivity Commission to ensure that there is no loss of the innovation and strong practices in place throughout regional WA.

CORDS service providers have worked for many years to address the inequity in regional, rural and remote areas by creating innovative and responsive services that are unique to each region. We urge the commission to support and build on these existing resources and support local service providers by providing some certainty of infrastructure and recognition of existing innovative service models, whilst organisations additionally move towards self-directed funding under the NDIS system. In fact regional WA would be a perfect choice for a trial of the NDIS in regional, rural and remote areas given the collegiality of our CORDS members.

Whilst CORDS supports an individual's right to an independent assessment, we consider it imperative that the assessor has local knowledge of the region involved. We consider it vitally important that assessors are based in regional, rural and remote areas to gain a first-hand account of the circumstances and issues of each individual in relation to their community. An assessor with limited local knowledge would not be equipped to assess the person's needs; conversely, an assessor with a longstanding connection with the local community would increase the likelihood of a fair and reliable assessment.

To equitably provide national consistency and enable portability, the commission needs to consider the additional costs involved in living in a regional, rural or remote area. A person's needs assessment in the metro region will be considerably different and inequitable if moving to a regional, rural or remote area. There's no obvious indicator as to how the additional costs associated with this delivery in regional, rural and remote areas will be acknowledged. Costs will vary according to the region and geographic isolation, so one formula applied to all organisations outside of a major city would prove problematical. Even being one and a half hours from a major city raises challenges in service provision not experienced by metro based services. If funding is to be individualised, then consideration has to be given to regional, rural and remote situations where congregate care is not always possible. Assessments for funding accommodation services must be based on each individual's circumstances within their own community, unlike the current benchmark system where one size fits all and is based on congregate care in a metro based region.

CORDS consider that some of the innovative individualised services in existence should be retained, and that is, as was said, don't throw the baby out with the bathwater. Many of these existing supports have been achieved through innovation and adaptation and should not be lost as a result of the introduction of a new system. For example, we have block funded programs run in school holiday programs for kids with disabilities and their siblings. I can tell you one comment after one of the adventure activities with the kids and the siblings on the way home, a little girl said to the support worker who was transporting her that she thought she was the only one who had a sister with Down syndrome. Living in a small country town, people aren't exposed to that.

MS SCOTT: Yes.

MS MILLER (CORDS): We have other examples, young adult response services, which is an innovative program allowing young adults aged 17 to 25 to choose their own respite services tailored to their interest and for many of these young adults, it's the first time and their first step towards independence and having some control over their lives, rather than simply being told where and when and how they're going on the respite break. So far from undermining choice, these innovative brokerage programs promote freedom, equality rights and dignity for people with disabilities.

Supporting existing innovative practices is imperative, whilst also finding better ways of providing good support under these difficult circumstances must be a priority for further research and program development in the NDIS. It's about creativity of which country people are very good, to be given the chance to be flexible and creative, to not lose their existing innovative programs and services that already exist.

In assessing what supports are reasonable and necessary, CORDS consider that NDIS should have regard to the person's geographical situation and the equity arising from diseconomies of scale and of the increased costs of providing the full range of disability supports. The difficult circumstances of people living in regional, rural and remote areas should influence the types and levels of support provided. The assessment process should identify the adjustments that people living in these areas require. CORDS members regularly have cases where support workers have a round trip travel time of up to six hours to deliver two to three hours of support. Even living just an hour and a half from the city has a huge impact on the services available and the travel costs needed to access these services and to access developmental, recreational and social opportunities which are limited in small towns.

Specialist training and information for disability workers and organisations to support people with varying disabilities is compounded in regional, rural and remote areas. The cost of sending a disability worker to city based training or bringing the training to the region is extremely impactful on people's individual funding and the disability organisation's training allocations. CORDS urge the commission to ensure that the additional costs of training, given the diseconomies of scale for disability workers in regional, rural and remote areas be taken into account when assessing training subsidies for individual funding to people with disabilities.

Whilst CORDS is pleased the commission gave consideration to rural areas in chapter 8.4, we're concerned that no specific recommendations were made regarding these considerations. CORDS urges the commission to reconsider this and make a recommendation regarding chapter 8.4 to ensure that people with disabilities, their carers and families, can be assured that they will receive equitable services and supports of their choice in their own community without the necessity of relocation as the commission suggested on page 8.52, the second-to-last sentence.

MS SCOTT: Okay.

MS MILLER (CORDS): People want to live in their regional, rural and remote communities. They have greater opportunities for meaningful community participation and involvement, a sense of belonging and should be supported to do so. People's contribution to the community in which they belong is productive and enhances the community itself.

For many people in the country they are third or four generation farmers. They have always lived on the land. To have a child born with a severe disability means they can be expected, as stated on page 8.52, to relocate to the city. For these people this is just not an option because farming is their whole identity. They simply would not know how to live in a metro area. They would be isolated from their families and community, suffer more depression and suffer health problems which compound the ability of the family to cope.

In conclusion, CORDS urge the commission to make a recommendation regarding chapter 8.4 that any legislative formula should take into account the higher costs arising for diseconomies of scale of living and providing supports to people with disabilities living in regional, rural and remote areas of Australia when determining prices and individual entitlements and that these costs vary from region to region. CORDS urges the commission to make a recommendation regarding chapter 8.4 in relation to continuing or establishing block funding or an innovation fund to service providers in regional, rural and remote areas to ensure continuity of existing innovative programs, certainty and equity of service provision for people living in these communities given their specific circumstances. Thank you.

MS SCOTT: Thank you very much. Right, well, John, do you have some questions?

MR WALSH: No, I think that was very clear.

MS SCOTT: That was a remarkably good presentation. Thank you very much.

MS MILLER (CORDS): Thank you.

MS SCOTT: It told us where we got things wrong in your view and suggested how we'd make it right, so that's very clear. Karen, whatever examples you can give of these innovative arrangements we'd welcome.

MS MILLER (CORDS): Yes.

MS SCOTT: You know that we have acknowledged that we would expect higher costs in non-metropolitan locations. We have thought about flexibility. We are conscious that people want to be in their community. I've looked back at page 8.52

and it does read - looks in an unkind light now that I've heard your words. But I just want to bring us back to one point which I do think lies behind that. We do say on that page "very complex needs". You talked about equitable service and you've also used phrases like "diseconomies of scale". I've got diseconomies of scale in my mind and I've got that clear, but I want to go back to equity of service. For some things that would be perfectly reasonable: attendant care, supporting schooling and so on. But for very specialist therapies how do you see equity of service operating when therapists are so thin on the ground? What's your suggestion there?

MS MILLER (CORDS): We were hoping the commission can assist with that. You did make some very good comments about sharing resources - - -

MS SCOTT: We did, and we did talk about fly-in services where that needs to occur.

MS MILLER (CORDS): Sure.

MS SCOTT: So I just want to check. In terms of equity of service is it CORDS' view that that means metropolitan quality or is there an acceptance that maybe one of the trade-offs for stronger community is that it's not necessarily feasible to imagine that metropolitan services are going to be evenly distributed across rural, regional and remote Australia. I just want to check what you consider equity of service is.

MS MILLER (CORDS): Sure. I think your idea of bringing services out to regional cities is great. It would improve the inequity there now. However, even for families to access a regional centre can involve a round trip of 400 kilometres for that family.

MS SCOTT: Yes.

MS MILLER (CORDS): We are realistic. There will never be equity of service at their doorstep. But we have families with high support needs living in regional communities in their own town on their farm now and they are supported to do so and very successfully, so we don't want to lose that.

MS SCOTT: No, I understand. There's never any intention in our work that services would go backwards, it's all about improving the quality and having a more equitable provision of services. So I was very taken by the figures that you gave at the start, they're very significant. John, I might stop there. Is there anything you would like to further ask Karen?

MR WALSH: No, thanks, Karen. We haven't had a presentation that clear about rural and remote areas, so thanks very much.

MS MILLER (CORDS): Thank you. Make sure you read our big submission then.

MS SCOTT: Yes. No, that was great.

MS MILLER (CORDS): Thank you.

MS SCOTT: Thank you very much. Well, unless there is a late starter, and it doesn't look like there is, I now draw our hearings to a close. Thank you very much for all the participants who are here today, people that have come and gone and those that have stayed. I can't reinforce the importance of us getting your good input, because we've got a challenging task ahead of us and we do rely on your learned experiences for us to be able to do our work well, so thank you very much again.

MR WALSH: Thanks, Patricia.

MS SCOTT: Thanks, John.

AT 5.16 PM THE INQUIRY WAS ADJOURNED ACCORDINGLY