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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

DRAFT REPORT ON DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT SYDNEY ON THURSDAY, 14 APRIL 2011, AT 9.26 AM

Continued from 13/4/11

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MS SCOTT: Good morning, everyone. Welcome to today's public hearings. My name is Patricia Scott and the associate commissioner for this hearing is John Walsh. We are happy to be referred to as Patricia and John. So don't feel you have to use the word "commissioner". we'll probably look around, wondering who it is. Are there any representatives of the media here today? All right.

We are making a transcript of today's hearing, because there will be other people who will be very interested in hearing and seeing what is presented today. You are not required to take an oath, but you are expected to be truthful in your remarks. Transcript of today's hearing will be available on our web site pc.gov.au in a few days' time. Written submissions are required to be with the commission by 30 April, please.

I welcome to the table Fiona Barnett. Fiona, we have got about half an hour to hear from you. Would you like to make some opening statements, and then we might have a few questions for you.

MS BARNETT (APCP): We wish to thank the commission for the opportunity to provide further clarification to our original overview submission, which indicated the need for prosthetic services to be brought under the national banner of the proposed national disability insurance scheme. Initially I wanted to provide a few clarifications, and then answer the questions that you will hopefully have for us. At this hearing today I will use the term "artificial limbs" rather than prostheses, to describe the assistive devices that we are talking about as I don't want any confusion as to the types of services that we are talking about being funded by the NDIS.

We were really pleased to see that the commission considers that the NDIS should fund artificial limbs and that you have sought feedback on the desirability and practicality of this option. As part of the draft document, you have specifically requested an indication of what items should be included in the NDIS. Our submission is that all external artificial limbs, those that replace the function of arms and legs, should be included under the NDIS. I have brought a couple of samples of these to give you a representation of what I am talking about. These are devices for individuals, specifically in the lower extremity, from the metatarsal head, so where people have lost their toes and further back.

One of these two devices I have brought is for a person who has lost their leg above the knee, and one is for a person who has lost their leg below the knee. Of the two devices on the table here one is for a person who has lost their limb below the elbow; and one is for a person who has lost their limb below the shoulder joint, so an above-elbow prosthesis. The reason that I have brought these along is to remove any confusion as to the types of devices that we are recommending for inclusion. Our devices are actually considered class 1 within the TGA classifications, so this may assist with the understanding, as this means that they are non-invasive medical devices. As we have indicated in our overview submission, we believe that the NDIS will - - -

MR WALSH: Sorry, Fiona, could I just interrupt for a second? Could you give us some examples of what, other than class 1 non-invasive devices, what would be considered prostheses that you wouldn't include. Or are you going to get to that later on?

MS BARNETT (APCP):   No, I'm happy to answer that question now.

I think what we felt the confusion was is that prosthetic devices are both internal and external, we wanted to make our submission to specifically state that they're external prosthetic devices. So things like hip joints, for example, which are internal prostheses, like, with your teeth it's called a prosthesis when you actually have a tooth assisted in the implantation. So that's an internal device compared to an external device.

As indicated in our overview submission, we believe that the NDIS will ensure appropriate services, focus and governance of ongoing care for all amputees, regardless of their cause of amputation, and that it will prevent the limitations of the current fragmented systems that are in place. One of the points that we wanted noted was that there is no external funding at this point for clients with limb amputation. There is no private health scheme funding available for clients with artificial limbs. As the commission has also noted, there is a postcode lottery in many areas of disability services. Artificial limbs is no different. An amputee will receive access to different assistive technologies based on the state in which they live and the cause of amputation.

Today, as we have limited time, I thought I'd just give an example for an amputee that has an acquired amputation through a planned procedure rather than a car accident or a congenital deficiency. There is complexity to the journey, but we must view the journey of the amputee as lifelong management from the point of decision to amputate, and we must take into account all aspects, from the intensity and complexity of the acute phases of care and rehabilitation to the changing needs of independent working individuals as they age.

This complexity should not scare us off from creating a national artificial limb service, and I did want to clarify an error in our original submission. The error was that we stated that there was a case mix model available for amputees, and we now understand that it was never fully developed. It appears that the complexity of how the NDIS should include artificial limb services is not about whether a national service would actually provide equality to all Australians and that that's actually a good idea, and it's not that we shouldn't abolish the challenges of underfunded state services or postcode prosthetics; the complexity appears to be in how do you actually fit lifelong management into existing underfunded services in acute care and beyond.

We all know that amputation is for life. There are assessable needs though throughout the journey, and I guess I wanted to provide just a brief idea of how this concept of bringing in to our services the full continuum. So the NDIS has actually proposed trainers and assessors along the phases of a journey. As I said, amputation is full of stages. The document in front of you shows that that the first 10 per cent of the journey is in the acute phase, and I think this is what has created a lot of complexity in our thinking. 90 per cent of the journey is what we call lifelong management.

Currently we have loose definitions; we tend to call it interim stages and definitive stages. There is diverse funding in both of these phases, and it's the diverse funding divide that has often led to challenges for amputees. While there are a number of ways that this program could actually run, I would like to highlight this proposal, that rather than have minimum requirements of care prior to the admission of the NDIS, which is one of the things that currently is required in various states in Australia, that we actually need a seamless continuum of care rather than the postcode lottery that we currently have.

What you will see in the document before you is an example or a suggestion as to how to deal with the initial phase of amputation. We know that coding for surgical amputations are a national procedure, it's under the Medicare model. The potential for us is to utilise this coding to access initial funding from the NDIS at this stage of service. This would add the prosthetic device, or the artificial limb, and the immediate post-operative management devices, but it would not require us to fund the actual acute phase of care that is being provided by the current state health services.

We know that a nationalisation of the service alone would bring assistance to all amputees in Australia. It would ensure equality across all services. It would ensure that people are not disadvantaged by their geographical location. We would recommend that it is a centrally administered but locally delivered service, which would significantly reduce the duplication of administrative requirements. We believe that this would assist us in better managing funds and improving services, especially given the utilisation of a national database of information.

So with these thoughts in mind, we urge the commission to keep in mind the journey of the amputee, not just simply the devices involved. But we do believe that the complexity can be clarified and that the ability to provide a national service to all amputees is vital. I hope to answer any questions that you may have regarding our original submission, and we actually seek to further understand the details that you need for our additional submissions in order to ensure that the NDIS could administer services for people with an amputation.

MS SCOTT: Thank you very much, Fiona. You are on the money, we were having the confusion about internal and external, with so many other devices, you know, knee joints and hip replacements. So the clarification is very good. Someone presented to us relatively recently and suggested that it shouldn't just be the limb, that there's quite expensive socks and other complementary elements. Do you have a view on that. Maybe if your view if that they should also be included, you might add them to your further submission.

MS BARNETT: I can clarify I think the comment about socks specifically, with one of the devices that I have. The device that I'm actually holding in my hands has two parts to it. If you think about when you wear a shoe, you always need something, a sock, a stocking; unlike certain shoes, thongs, you don't need any connecting device. For an amputee, they actually need that point of connection to ensure skin integrity, to ensure health. One of the key things about a prosthetic device is creating a weight-bearing surface on an area that was never originally intended to weight-bear.

If you think about the sole of your foot, we have quite a hard skin on the sole of our foot. The areas that we utilise to weight-bear in a prosthetic device don't have the same integrity as the sole of our foot, so we have to artificially create that integrity. The technology that was developed in the 80s was a silicon sock; it's called a roll-on silicon socket. This replaced socks for the majority of people and it also changed the way in which we designed prosthetic devices. The use of that is integral to the prosthesis, because if you look at in this case, the sock is actually also the suspensory mechanism to actually hold it on with that type of sock. There are different types of devices and different ways of suspending a prosthesis; and that's probably why people have talked specifically about socks, it's because it actually assists with maintaining the health and integrity of the skin.

MS SCOTT: That's very clear. Thank you.

MR WALSH: You have got a variety of types of prosthetics, Fiona. Are there any other add-ons? Do people wear shoes as well over their prosthetics? I'm just trying to get a handle on what is the whole requirement when someone has an artificial limb.

MS BARNETT: Probably the easiest way to answer that question is that people will use shoes with it, but the advantage of a prosthesis is that we have removed the foot as such, so we have standardised designs for the feet themselves, so they're a standardised covering. So for the actual prosthetic device, you tend not to need assistance with footwear. Often people have contralateral injuries and there are often needs for assistance with those types of devices. So while I'm not particularly talking about orthotics today - which is another aspect of this question, I'm sure - for an orthosis you do tend to need an adapted shoe.

MS SCOTT: We heard in Tasmania from a gentleman I was thinking got a prosthetic device, but maybe it's an orthotic device. It cost $3000 and ensured that he was able to effectively get movement propulsion from his foot, effectively a mechanical device, that he couldn't have got previously, it was expensive. He was a polio survivor, and it made a difference. I suppose we have got this dividing line between orthotics and prosthesis, and maybe that is going to be our next issue to deal with. You don't have any comment on that? Like, for you, it is arms, it is legs, it's these things, and that is all it is.

MS BARNETT (APCP): From the artificial limbs, we currently have eight different systems across Australia. The reason that we have requested that prosthetics become a nationalised service within the NDIS is specifically to assist with arms and legs.

MS SCOTT: Could you tell us a little bit more? I understand the history of this, and from your submission earlier and even from your slides, this was a responsibility of the federal government, there was a national scheme, there were national standards, and because it resided with Department of Veterans' Affairs, I think for some time - - -

MS BARNETT (APCP): Correct.

MS SCOTT: In a shift of responsibility, it became a state responsibility.

MS BARNETT (APCP): Correct.

MS SCOTT: Then effectively over time you have had then states moving in quite different directions, in terms of the level of support, what is provided, waiting lists and so on. So we now have quite a fragmented arrangement where two people in different states could end up with quite different levels of servicing. Could you talk about the variations of standards between the states? Are you able to talk about that? You'll try?

MS BARNETT (APCP): I'll give it a go. My understanding of when the devolution came down to the states is that there was a funding model for each state based on a historic number, and so the value to each state started with a certain amount of money, to which their service could be provided. Different states received different levels of funding that were quite significant. Queensland was probably one of the most underfunded services at that point in time. So their ongoing budget has just been CPI'd from that original number.

This meant that there has to be a lot of creativity from the service manager to be able to provide different levels of service, and I think what we have found across Australia is that we have been able to have people with different levels of creativity in their ability to manage their budgets. For example, there are bright spots around Australia. I would state that there is not one service in Australia that we could model effectively and create an Australia-wide service, but there are definitely bright spots in various parts of Australia that can assist us with different models. In our submission we have mentioned two specific places that we thought had good potential to be viewed as bright spots in certain areas.

MR WALSH: Just for the record, could you tell us what they are.

MS BARNETT (APCP):   In our submission we have stated that Caulfield Medical Centre and the Orthotics and Prosthetics South Australia have been doing good things with their services in certain areas. So Caulfield Medical Centre, in my opinion, they have got a good early management program that works very well. The Prosthetic Service in South Australia also have a good early management system, which is why we particularly highlighted those services, in our submission, because it's wanting to create the whole journey for the amputee, as part of a national service, which I know is a challenge, because it crosses funding divides.

MR WALSH: Fiona, I'd just like to understand a little more about the 10 per cent/90 per cent divide and the journey. You mention that there is a Medicare item number, so effectively I assume someone goes in, has a limb amputation and there's a Medicare item number that say, "Okay, you've lost a leg, you're entitled to this." Right?

MS BARNETT (APCP):   I apologise for the confusion. It's the surgical code I was talking about.

MS SCOTT: Like, under the health agreement there's a medical code for a particular - - -

MS BARNETT (APCP):   My brother is a surgeon, so if he amputates in Victoria or Queensland, he would write the same code under Medicare. It was that code I was indicating.

MR WALSH: Does that code include the artificial limb?

MS BARNETT (APCP):   No.

MR WALSH: So who pays if someone has a leg amputated in a public hospital in one of the states?

MS BARNETT (APCP):   Who pays for the surgery or who pays for the device?

MR WALSH: For the device. Does someone actually get a device?

MS BARNETT (APCP): There are different systems across Australia. Here in New South Wales it currently went a tendered service and EnableNSW now funds, as an extension of their original budget which was only designed from three months post-amputation, they've now taken their funding and attempted to provide an interim service as well, with my understanding no real increase in their budget. So they've expanded where they serve without having a real increase in the amount of funding that has been provided to them. In Victoria, and in most states of Australia, there are various abilities to find pots of money that bring together their service. In Victoria, as with every state, you have an artificial limb either scheme or program or some format.

People have been creative in the way in which they have been able to fund their services by finding pots of money to do what they need to do. This is why we are hoping that the NDIS will assist us in a nationalisation because realistically since the devolution down to the states there hasn't been a true representation of cost for prosthetic services. As we've increased our ability to serve amputees better from a prosthetics profession we've been hamstrung, for want of a better word, to be able to provide those services because you've got this funding divide, you've got bed stays funding the amputee services rather than a specific process.

MR WALSH: So what you're looking is that someone goes into hospital, has a limb amputated, the NDIS provides the device that goes with that surgery. Yes?

MS BARNETT (APCP): Yes.

MR WALSH: That is, I guess, similar to someone who becomes a quadriplegic or paraplegic, the NDIS would provide a wheelchair.

MS BARNETT (APCP): Correct.

MR WALSH: Just on another topic, if you've got any information on the number of amputees that have a need for a new artificial limb every year and the rough cost of those, that would help us.

MS BARNETT (APCP): Numbers, as you know, is always a challenge for anybody to achieve. What I pulled out was actually some numbers based on the New Zealand Artificial Limb Board's information. These reports are publicly available. They are on their web site, I think it's nzalb.co.nz. I pulled out their budget, their number of clients and their population and I did an extrapolation of that into all the states of Australia based on population taken from wikipedia to look at the equivalent budget. So while I don't have the exact data, I can provide you with that and we can provide links within our additional submission.

MR WALSH: That would be very useful, thank you.

MS BARNETT (APCP): It is just a very simple way of looking at it. One of the challenges that we have with the fragmentation of our services is an inability to draw the data together. One of the beliefs that we have, and we have put specifically in our submission, is that a national database would assist us not only in understanding what best practice will be for our clients, but it will also better assist us in understanding the costs that are actually involved.

MR WALSH: That's great, thank you.

MS SCOTT: Fiona, yesterday someone suggested to us that while rehabilitation could remain a hospital expense and covered by the Commonwealth/state hospital agreements, the slow rehabilitation - - -

MS BARNETT (APCP): Slow stream?

MS SCOTT: Yes, slow stream should be an NDIS-type expense. Do you have a view on that and is it relevant to your areas of interest with prosthetics?

MS BARNETT (APCP): I think I saw that as part of the 10 per cent time frame for the amputee.

MS SCOTT: All right.

MS BARNETT (APCP): I talked about acute care, the amputation itself, acute rehab and the outpatient rehab. I specifically used "outpatient rehab" compared to acute care rehab and I think that indicates the slow stream rehab that we're talking about in this situation.

MS SCOTT: Is there maintenance on artificial limbs?

MS BARNETT (APCP): Absolutely.

MS SCOTT: Who pays for that currently in New South Wales?

MS BARNETT (APCP): EnableNSW under the Prosthetic Limb scheme.

MS SCOTT: Is that a significant item? We've got to try and cost all these things.

MS BARNETT (APCP): I think there are a couple of things that you have to understand with an artificial limb that I haven't particularly alluded to today. We are integrating, externally of course, with the body and the body is a changing system. Often we have changes specifically in the shape of what we call the residual limb or the stump, there is ongoing changes. That is dependent on the client's health. So if somebody has put on a significant amount of wait, we actually need to change the device. If they have lost a significant amount of weight, we have to change part of the device. These devices are mechanical. So in the same way as you require your car to be serviced, you will require your artificial limb to be serviced. These are mechanical devices. So from any mechanical stress testing, there is a need to maintain and service them.

MR WALSH: Do you have any idea of an average - how often would someone need an artificial limb replaced, for example?

MS BENNETT (APCP): Again, depending on the cause of amputation. It's generally in the first two of years of life that you need a number of replacements, depending on the type of early management that you have actually received. We call that early phase the need for therapy that actually compresses and removes the oedema, which is the fluid that comes into the stump at the point of an amputation. It's suggested that it takes about 18 months for a residual limb to actual settle to what we call a mature stage. Through that first 18 months, depending on the type of compression therapies that are available to you, you could need two to three socket replacements as opposed to limb replacements. So the actual point of connection is where you would need assistance and changing.

At one point in time in Tasmania we demonstrated that with the use of removal rigid dressings that they have an average of 1.5 replacements sockets but they were a system where they actually immediately post-operatively utilisation of a removable rigid dressing.

MR WALSH: Once the residual limb has stabilised, so two years after amputation, for the rest of the life is it once every two years, five years?

MS BENNETT (APCP): It's an average that is hard to provide. Currently we're funded every three years for a device; that we're able to fund a device every three years. I think if you talk to some of the managers of the artificial limb services around Australia, they would suggest that it's more likely to be two years than three years with a socket replacement. The three years also is based on cyclic testing in the concept that these are mechanical devices. So the replacement of the device is required because the expectation is that they would have been through their - do you understand the ISO standards?

MR WALSH: Yes.

MS BENNETT (APCP): So the need for cyclic testing, the use of those ISO standards require us to replace the mechanical pack factors.

MR WALSH: These numbers you have given us, are these new artificial limbs only are they replacements?

MS BENNETT (APCP): No, that number that I used was basically the number of clients over the budgetary time of the - - -

MR WALSH: So this would include replacement?

MS BENNETT (APCP): If you look at their web site specifically, they actually have a breakdown. One of the good things that I highlight about the NZALB is in the last five years they have put together a national database. Their statistics are very good. They can tell you how many vascular amputations, how many cancer clients have been amputated. They can then tell you how many socket replacements versus how many limbs that have been replaced in their system. Those numbers I put together, as I said, were quite gross. It just was a way of indicating - - -

MR WALSH: They looked pretty impressive to me, so thanks very much.

MS BARNETT (APCP): But I would encourage you to look at the NZALB's web site.

MR WALSH: I don't have any more questions.

MS SCOTT: I have a list of unresolved issues I want to check on.

MR WALSH: While Patricia is finding that list, Fiona, could you talk a little bit about - I know you're only speaking today about prostheses and external limbs - your view on where something like functional electrical stimulation would fit in terms of the NDIS providing artificial devices.

MS BARNETT (APCP): I don't have a good understanding of FES, so I don't think it's appropriate for me to comment on that.

MR WALSH: That's fine.

MS BARNETT (APCP): I'm sorry.

MR WALSH: That's fine. Thank you.

MS SCOTT: Can I just check whether this information jells with your understanding. So for a fairly standard artificial limb, we could be looking at 5000 to 15,000 below the knee or up to 70,000 for very high-end above knee apparently quite sophisticated artificial limbs. Is that about right?

MS BARNETT (APCP): Can I clarify a couple of things in your language first. Technology is changing continuously. The numbers that you state are for basic technologies and for advanced technologies that have been developed. The $70,000 is more towards technologies that have been developed since the - actually that specific device was developed in the 1980s, but you'll find there's a lot of research now showing that people who are at a low end of activity are actually doing better when they're provided with better technologies.

So I guess I'm concerned about the word "high end" in that, primarily because we need to fund what is appropriate for the client. I was explaining that I had a phone call with somebody yesterday that said to me that said to me, "I want to make sure I've got the best," and I explained to the client on the phone that, "It's actually not about what is perceived as the latest thing on YouTube, but what is the most appropriate for you in your everyday activity and your lifestyle, what will best assist you to get back to work, what will best assist you to do your job well." Often that will mean, rather than provide the most expensive widget that's out there, it's about providing the most appropriate device possible.

So while your numbers are ballpark, at this point time, yes, my concern is that historically those numbers have been built off what we could fund, rather than what was most appropriate for the clients. One of the things I liked about your draft report was that you said, "We could just throw money at this, but the reality is we need to put money and thinking behind it." It's the thinking that I want to encourage and we want to be involved with, because it's the thinking that will help us better use our tax dollars to provide better services and better outcomes for amputees across Australia.

MS SCOTT: Fiona, thank you very much and thank you for bringing in the items. It certainly does clarify things for me, coming from a very low level of understanding, so thank you very much.

MR WALSH: Can I just ask a question. This is probably a very stupid question, but I'll ask it anyway. The two upper limbs you've got there, the below one actually has a hand and fingers and the other one doesn't. Why is that? Will the other one get hands and fingers or is that just the way it will finish or - - -

MS BARNETT (APCP): Unfortunately, to fund an above elbow with hands and fingers that are very functional, you need to use the latest technologies that we have available in the world today. A hook is still quite a functional device. It's not a very cosmetic device. It's something that a lot of upper limb amputees have to come to terms with from an emotional and psychosocial response. There are passive devices. This is a passive device, so it's simply there for a cosmetic purpose. This is an active device, which is a functional device.

The most functional hand devices are coming out of the US at this point in time. If we can thank war for anything, which I'm not quite sure of, the assistance to prosthetic development is that there's been a lot more funding available for development and we've coming to a stage where the degrees of freedom that are available in the function of the hand is just so complex and we're starting to be able to provide devices that are able to do that. Unfortunately that level of funding is currently way outside the availability for those clients who are publicly funded in Australia. If you look at the difference between a publicly-funded client and a third party insurance client, you'd find that they're very unlikely to receive a device like this.

MS SCOTT: Maybe we should explore that a little bit more. Referring to those costs I quoted earlier of five to 15, but more sophisticated 70,000, if you were in a motor vehicle accident covered by a no-fault scheme, what sort of cost for a corresponding limb function, the one you've got there, would you be looking at in terms of likely cost of a more sophisticated device that would be used in Australia typically in no-fault based schemes?

MS BARNETT (APCP):   An upper limb device, something like an i-LIMB, you are again looking at that 70,000 mark.

MS SCOTT: Is it just an aesthetic - - -

MS BARNETT (APCP):   No.

MS SCOTT: It's not. Can you talk about that for a minute.

MS BARNETT (APCP):   My ability to pick up a cup means that I can actually curl my fingers around this, so the different forms of prehension that are available to us with our hands and with the movement of our fingers is significantly different to the ability of a single device and precision. The ability to do different functions with your hands is dramatically different when you have a device like this, compared to one that will do this.

MS SCOTT: Would there be increased cost in the 90 per cent area with the more sophisticated device because there's more training involved or because there's more maintenance involved?

MS BARNETT (APCP):   The cost of maintaining a device. Is that your clarification?

MS SCOTT: Yes.

MS BARNETT (APCP): I guess it's a percentage of the cost of the device, yes, so I think the simple answer to that is yes.

MR WALSH: And replacement. So you would still need a replacement every two or three years of the $70,000 device?

MS BARNETT (APCP): Definitely the socket, depending on what's happening with the technology and what you're doing with the device.

MR WALSH: Is the surgery different? Presumably to make use of the functionality of the device, that's nerve-driven from somewhere, so is the actual way in which the nerves are attached to anything different?

MS BARNETT (APCP): With the current commercially available devices, no. You actually use a signal from your muscle signals. We call it myoelectrics. So a specific movement triggers the electrical impulses that assist the device's movement. Some of the surgery that has been done in the last seven or eight years has been where you can actually physically change the position of a nerve site to then have an electrode connected to it that will then assist with the development of the movement. I believe that surgical technique is going to develop, it's one of the innovations that are being driven at this point in time. As I said, the current wars have provided a lot more people that need upper-extremity services and therefore there has been a lot more thinking and rethinking about how that works.

It's a good indication too of the importance of the rehabilitation team around the client and throughout their journey. It's not just about the prosthetic services that, as clinicians, we provide; it's the importance of the holistic team behind them: the rehabilitation consultants, the physios, OTs, social workers, psychologists. That's part of the lifelong journey. People can get through the first phases of becoming a person with an amputation, but four or five years down the track sometimes they need a little bit of help emotionally to deal with some of those issues, so it's important to keep the holistic team. One of the suggestions we've made is for a national body to incorporate all those people.

MS SCOTT: You talk about a national body. One of the problems that we've got with the currently fragmented system now is that people have to fit the criteria of particular funding buckets rather than be assessed for what they need on a reasonable basis and then services, therapies, or aids and appliances are then provided to them. So your thinking of the service or this group of people, is that along the lines of a New Zealand model, where you have an ACC, but within that you might have areas of specification. You're not seeking to set up an entirely separate arrangement from the NDIS, are you?

MS BARNETT (APCP): The ACC and the NZALB are quite different. In

New Zealand there's an artificial limb board, it's a crown entity and their services are run across the two islands of New Zealand. There are some positive things about the NZALB and there're some things that I'd love to improve on as well. In my understanding of it, the ACC though is actually more like a TAC here in Australia or a CIO.

MS SCOTT: Yes, that's true.

MS BARNETT (APCP): It's actually an insurance organisation, which I guess I thought of more as the NIIS structure that you have proposed.

MS SCOTT: Yes, I think that's probably true. But I just want to check, in the model you're envisaging, with people that currently have artificial limbs, in our draft report they would be interacting with the NDIS?

MS BARNETT (APCP): Correct.

MS SCOTT: We were envisaging funding within the NDIS and you're suggesting 90 per cent of the total care would be in the NDIS. You're not suggesting it be done as a separate authority from the NDIS, are you?

MS BARNETT (APCP): That would be nice; I know that it's not possible.

MS SCOTT: Okay.

MS BARNETT (APCP): I understand it's not possible. To explain our thinking behind this, was that we currently have state-administered services. Rather than having the fragmentation of the eight states, take a body centrally that would draw all those together but would be delivered on a local basis.

MS SCOTT: One of the issues that would arise if it was a separate body again is that over time you would have a board for artificial limbs, then a board for orthotics, and then you'd be back to the funding buckets and so on. All right. So the New Zealand Artificial Limb Board - - -

MS BARNETT (APCP): Is one of the groups that would get statistics for you, yes.

MS SCOTT: That's very useful.

MR WALSH: Maybe in your written submission, Fiona, you could tell us what is not good about the New Zealand Artificial Limb Board, what things would you improve in it.

MS BARNETT (APCP): Currently they don't take the whole continuum of care;

they're not actually in that first phase, that first 10 per cent. If you look at their website they actually have a recommendation of how they could be, but as yet they're not in that stage.

MR WALSH: So we'd need to increase these numbers to include the first 10 per cent, yes.

MS SCOTT: Someone else has suggested to us that the integration of prosthetics with other medical aids would be an improvement, but you don't have a view on that?

MS BARNETT (APCP):   If you mean orthotic devices, wheelchairs, and disparate services, I don't believe it should be under that.

MR WALSH: So the NSW Enable system, where they are together, you don't think that is a good model?

MS BARNETT (APCP):   Since the transition we have had more challenges with working for our clients. We don't fully understand how the division of funding is working; we're told that they're disparate funding pockets, so the funding, while Enable is funded, there is a designated amount for prosthetic services. We've been less able to understand how that funding is delivered since it has become part of EnableNSW, which is why our statement is that we don't think there is one service as such.

MR WALSH: Is that the main issue, that it's a funding issue?

MS BARNETT (APCP):   The other thing that's happened since it became EnableNSW is they've changed the way in which - there were historically a number of different committees that could feed information in and could feed forward and feed back information. While we know that all committees have their challenges, there's been more of a bureaucratic approach, from my perspective, since it's become EnableNSW, because they're trying to build committees that are for every single service and so prosthetics once again becomes the minority within the minority of disability services.

We're a small group, we acknowledge that, but we're often hidden in the community, for a transfemoral amputee, for a male, they just need to put on a pair of pants and people think they've got a sore knee. People don't understand the challenges that they go through every day to get out and get to work. We work really hard to make that a possibility, but we just feel that we need more support for our clients in their everyday activities, which is why we believe that NDIS would be a good thing.

MR WALSH: Thank you.

MS SCOTT: All right. Thank you very much. Very helpful.

MS SCOTT: We might resume now and I'd invite everyone to take a seat. We'll now welcome to the table Diane. I understand you're representing yourself?

DIANE: Yes.

MS SCOTT: Please commence.

DIANE: I have an 11-year-old son with a severe intellectual disability and it's my experience as a carer that I bring to this hearing. I have put in a written submission in respect of the draft report, but I did want to reiterate a couple of general points on that. Fundamentally I endorse the draft report of the Productivity Commission. It's a fantastic step forward. Self-directed funding is so vital. But a national program which really looks to meet needs, rather than just setting a meagre budget at a state level is definitely needed. I had some constructive criticism to make in respect of the draft report broadly under two themes. One was to just add some more real world practicality of living with disability basically to some of the issues that were raised in the draft report.

The other broad theme on which I would make submissions is, similar to the lady who just spoke about prosthetics is don't forget about the people with very severe intellectual disabilities and very high support needs, because we are a small group, but we will have a serious impact on the NDIS because of the very high care costs which are relevant to our group. Because this group is really quite invisible in society, it can be overlooked. I don't suggest that you are overlooking it, but I think that there are a couple of issues on which the NDIS could go a bit further to assist vulnerable people with severe or profound intellectual disabilities.

On the question of adding a bit more everyday practicality of living with disabilities, the issues that I wanted to raise were to request some more clarification following on from the draft report in respect of the additional costs of everyday living that you propose to fit within the national disability insurance scheme in that I know from my own experience that we have extensive additional costs of everyday living which the health profession is unaware of and even therapists are unaware of. But the requirement for home modifications on a security-type basis, not a ramp for a wheelchair, but to address behavioural issues or for specialised clothing again to address behavioural or incontinence issues.

Things like that, doctors and therapists have no involvement in, no government bureaucracy knows anything about. Those costs exist, but you don't really have any background to draw on for how much they're going to be. But I thought the draft report was not entirely clear on where you were looking to draw the limits on the additional costs of everyday living in respect of people with disabilities and they're quite extensive. On that point, I also would submit that the rule proposed in the draft report to limit the ability of people with disabilities from making decisions that unreasonably increase costs for the NDIS was too broad a rule. There are a lot of issues that people wouldn't want to make in their everyday life which could increase the costs of the NDIS and there would be significant opportunity for argument as to whether it's reasonable or not. Things like moving to a remote area, choosing your own carer, even if they're more expensive, basically choosing to not have family care.

Those sorts of limits were not built into the rule as set out in the draft report. In the draft report was a very broad rule that simply said that people with a disability would be forbidden from undertaking decisions that unreasonably increase the cost of the NDIS. A number of parameters should be added to that to make clear that - or say there was a corresponding rule in the draft report that said that family care would not be coerced, would have to be willing. But without any clarification of your general rule about forbidding people from undertaking choices that would increase cost to NDIS, you would not actually be able to choose to not provide family care.

There are more important issues than that thought about where you live and things like that, but I think that a better rule would look to have the same effect of limiting people from unreasonably increasing the costs of NDIS, but making clear the limits of that rule, such that it does not then limit your choice of carer. It is supposed to address the costs of home modifications, according to the draft report, and that is sensible, but more precise rules about how often you could move after you've had a home modification or the extent to which you would be entitled to home modifications above the average would be a more targeted and better rule, rather than a very broad rule which would impinge upon other decisions.

MS SCOTT: Diane, do you mind if we have our discussion about that now?

DIANE: Yes.

MS SCOTT: I think you make a good point that the text at the moment could be interpreted to be too broad in its application. Clearly we were looking at the experiences of a number of funds where high costs were entered into because people made decisions about moving into houses with lots and lots of stairs, even though they had a child with limited mobility and in a wheelchair and the lifts and so on.

DIANE: I think it's reasonable to limit those costs.

MS SCOTT: But you're right. Does that preclude people from ever moving because family would like to take up different employment options in another location? That's a good point. So we can think about that, but it might be the case that in the time we have, we won't be able to really chase this down. It might be the sort of thing, if the scheme was in existence, that you would want the advisory council to the board to come up with some ideas that have an interest of trying to ensure sustainability of the scheme, but also sufficient flexibility for individuals and families. So I have to say my immediate response is you may raise a good point, but don't be disappointed if you find that we don't have a whole chapter or - - -

DIANE: No. One line which says, "It's not going to be as broad as this," at any point would be good.

MS SCOTT: Even a line which says, "This needs to be subject to further careful work and consultation."

DIANE: Yes.

MS SCOTT: On remote areas, that's a trickier one, I'd actually say, because we're very conscious that all sorts of people have complaints about the disparity in services if you live in a country area, the cost to fly in, fly out, how difficult it is sometimes to maintain good access to services. Therefore to have someone actually make a conscious decision that they're going to move out to an area where there are poor services, I think I would probably pause more about that one than some of the other examples that you gave.

DIANE: I agree. I'm just giving examples of the very broad areas that that rule could cover and that I think that more thinking is required to set more prescriptive rules to cover those sorts of examples where you know there's a big ticket cost of making a different choice. Yes, perhaps people should not be allowed to move to remote areas which are very hard to service. So I think there should still be limits, but you should think about the sorts of examples which we don't want to limit, such as should an adult man have to accept the care of his mother when he's 30 years old and he requires a lot of personal and intimate care, is he entitled to choose a carer who is a paid carer, not his mother, and things like that.

MS SCOTT: Okay. I've got that.

MR WALSH: Clearly if that's the message you've taken away, we need to be clearer. I think the report does try to accommodate that. There's not intended to be anything in the report that coerces families to be primary carers, so if that's the impression that you have, we need to have a look at it.

DIANE: No, I didn't get that impression. It's just that those two rules in the draft report are inconsistent - well, arguably - because, with your general rule that you're not allowed to unreasonably increase the costs of NDIS, the problem is that you don't know where that ends, right, and so then it could override the other rule that family care is a choice.

MS SCOTT: Yes, I understand.

MR WALSH: That's fine. Diane, just the other one. If you're comfortable to do so, if you could give us some idea of the additional costs that you talked about, the - - -

DIANE: Sure. In my case I'm not sure that I am at the high end of the additional costs, frankly, but I know from my circumstance that we have a lot of additional costs. The biggest ones I suppose are in the order of home modification; not home modification for physical disability, but home modification for safety and - - -

MS SCOTT: Absconding.

DIANE: Yes, to stop absconding and property damage. I mean, my child has quite extreme behavioural issues which require that his bedroom is like the modern padded cell, frankly. Everything is locked down. The bed is screwed to the floor. There's closed circuit infrared TV into the room, so that we can see what he is doing in the dark. There are bars on the inside of the window so that he can't break the window. There are block-out shutters on the outside of the window to create some darkness after you rip the curtains down. There are a lot of issues like that. I mean, I'm aware of some like that, but I'm sure there are examples in other people's facts where there are a lot of additional costs of everyday living, which are not obvious to the health industry.

MR WALSH: I think it's good to have that example for the record. I think that might be a good cameo of what sorts of things might be required.

MS SCOTT: Diane, do you want to say any more?

DIANE: The other general topic on which I had some comments to make was focusing on people with severe intellectual disabilities and very high support needs. On that topic, I strongly advocate that the NDIS legislation includes an empowered advocate role for the person who would ordinarily be the primary carer of a person who has decision-making disabilities or communication difficulties, such that they cannot independently interact with the NDIA in a way that the NDIA is going to need. You will need such an advocate role anyway for administrative purposes.

In choosing how to use the budget - like, say, my son cannot make that choice, and my husband and I got divorced, then we could argue about the budget, you know what I mean - you're going to need one person who is going to be the decision-maker for vulnerable people with disabilities - like my son, even once he is an adult - to do your admin, basically. You also asked in the draft report for suggestions on monitoring of quality under the NDIS. I think a strong legal empowerment of an advocate for vulnerable people with disabilities is necessary to ensure monitoring of quality as well. I hope my son will be in supported accommodation at some point in the future, but, say, it's possible that there would be rules that would limit my access to him once he is an adult; or, say, a community visitor has a right of unfettered access, unannounced, and I think that there should be an advocate empowered to do that as well for an individual - you know, on an individual basis - for vulnerable people with disabilities.

MS SCOTT: I just want to check this. I have read a bit about the Victorian experience, where you have Office of Public Advocate, and in some states you have a disability commission, sometimes with two distinct roles. Are you talking about that official capacity; or are you talking about how if your son went into supported accommodation you would like to be the designated advocate/guardian and that if you want to check on your son's quality of care you should have unfettered rights to be able to go and see him?

DIANE: I'm speaking about the latter, the individual advocate, because I think that is real everyday safeguard for vulnerable people with disabilities, because it's their family who is going to be visiting every day or every week and who are going to see the real story and have the facts and the loving relationship to want to ensure quality. But families, basically, will need to be empowered to do that, and I think that that would be a necessary monitoring tool, under the NDIS, for a number of reasons really. The guardian rules don't really go far enough and they're more on a exception basis, whereas the NDIS will involve disability service providers who can undertake a lot of very intrusive and personal activities in respect of vulnerable people with disabilities.

I am only speaking about vulnerable people with disabilities here. Like, those who can advocate for themselves can do that, and there are mechanisms under the NDIS. But those who can't advocate for themselves should have a legally-empowered individual advocate. Not everybody will have a family member who can and will do this, but a significant number will. But that individual advocate needs legal support to do that, to get past privacy laws and to be able to formally make a complaint, to be able to speak to employees of disability services, to be able to call for the documents that are necessary; like, there's sort of a suite of rights which will need to be placed in an individual advocate, in order to give effect to the monitoring of quality that really will be necessary under the NDIS for vulnerable people with disabilities, and it will be so much more effective at an individual level.

There is still a use for community representatives and so on, but we also have to think about the need for cultural change. Coming from our current disability systems where bureaucracies and disability service providers are paternalistic and overly-empowered, frankly, at the moment, as compared to carers, who are hopelessly disempowered currently, because they are so desperate and can't get any service. It's actually a serious cultural shift to try and persuade carers that they have an active role to undertake in monitoring the activities of disability service providers for their vulnerable family members with disability.

There's a real difference as well between the unsatisfactory institutional care that we saw 30 and 40 years ago, paired with an expectation of no family involvement. Unsavoury practices can get out of hand without people in there visiting all the time who can make a complaint. I think there is a real need for an empowered individual advocate for vulnerable people with disabilities. My son's case is more obvious because his intellectual disabilities are really quite severe. Those with severe and profound intellectual disabilities definitely need an advocate. The more grey area is those with mild and moderate intellectual disabilities, where they can make some choices which they can communicate; but to what degree can they really effectively protect their own rights, and that is a more complicated area. But I would like to be empowered as an individual advocate, and I think that that is an important monitoring device.

MS SCOTT: I have got that. Thank you very much.

DIANE: The other somewhat serious point I think of criticism that I have in respect of the draft report is that it does not increase the care costs for people with disabilities at the highest support levels over their lifetime. The highest level of paid care under the costing arrangements had an average daily paid care of eight hours per day for people who require more than six times a day involvement in core activities, or whatever it was called, right. So the highest level anyway was eight hours of paid care per day, which is obviously on average across a population certainly.

MR WALSH: That's an average.

DIANE: But it doesn't increase from the time they're 15 to the time they're 65 years old.

MR WALSH: I think that's an artefact of the presentation really. The idea is that there would be an individual needs assessment, which could change over a person's lifetime.

DIANE: Sure, but those costings are definitely not going to be anywhere near right. You know, even allowing for the fact that it is like a population, so it's on average the case that those who require more care will be offset by those who require less care, to not increase it over time implies that family support doesn't decrease over time. I think that that is patently false, that, you know, as the parent - - -

MR WALSH: I don't think that's the way the costing has been done, just for the record.

MS SCOTT: Let's see if I've got it right. John could probably explain it better, but let me see if I can have a go. It's like a snapshot. So there would be some people with an 11-year-old child with severe disabilities who will need a certain level of care and there'll be someone with a 25-year-old child and someone with a 36-year-old child, and your son will age and his needs will change, and it's almost as if you take it at that time, and another time it will be the case that your son represents the 25-year-old that was also at that snapshot. Am I being clear?

DIANE: Yes, I understand that, but it has an average paid care expectation, which gets to a maximum for the average - - -

MR WALSH: There's no maximum.

MS SCOTT: No, there's no maximum.

DIANE: No, I know it's only the average, it's only for costings, but I sort of want you to understand that those costings can't be correct, right. I know that some individuals will need more than that. The average has to increase over time, is what I'm saying, because - - -

MR WALSH: The point in time is a continuum of time.

DIANE: Except that the same eight hours applies whether a person with disability is 15 years old or is 64 years old.

MR WALSH: Maybe we need to clarify the way that's presented. But what you're describing, we understand that, we understand that people need more care as they get older, and I think the costing accommodates that.

DIANE: It's in table 14.6, if you want to flip it over.

MS SCOTT: Yes.

DIANE: Really it does not increase over time. I'm afraid I disagree with you, on a factual basis. But, great, if you guys think it should, fabulous.

MR WALSH: With respect, just for the record, you didn't do the costings, so you can't tell us whether it increases or not over time.

DIANE: Except that the table reflects that the average will be the same, because, on the table, say, it has people with different levels of required support - like, say, those who require more than six a day, and so on - but it also refers to the age of those people. So when a person is from nought to 14 years old there's a discount built into it, from the eight hours, because you expect parental care. But there is not an increase in the average from 15 to 64 years old.

MR WALSH: I think you'll find that we're not going to accept this argument.

DIANE: Yes, no, I agree, I'm happy to leave that there.

MR WALSH: You'll find that the distribution of people changes between the 15 to 50, and 50 to 64 group. So the average represents that different distribution of people.

MS SCOTT: It might be the case that we need to better explain what the table shows. I don't know if it's going to comfort you, but I think it actually - - -

DIANE: No, I'm happy to leave the issue.

MS SCOTT: - - - what you're drawing our attention to is reflected in the costings.

DIANE: What I'm drawing your attention to merely is that - - -

MS SCOTT: That it doesn't state that.

DIANE: Yes. People who need a very high level of care they can rely on parental support for a number of years, but we cannot expect sibling or spousal support, basically it's too hard and it just won't happen in practice.

MR WALSH: We understand that very clearly.

MS SCOTT: Good. Okay.

DIANE: I think it has been advantageous frankly that the Productivity Commission has looked at this issue of the NDIS, rather than in a sort of a disability bureaucracy, because of the freshness of the view given to the whole issue, and really my general point is that you don't see people with severe intellectual disabilities. I would bring my son to the hearing except that his disabilities are too severe to do so, such that we would not be able to participate in the hearing. My concern - in a small way, because I appreciate that you are thinking beyond just want you are seeing - is, you know, have you met any people with profound or severe intellectual disabilities, and keep those people in mind.

MS SCOTT: Got you. Thank you for coming along today. We appreciate that. You are obviously a very studied reader of the reports, so thank you.

DIANE: Lawyers do that.

MS SCOTT: I now call the New South Wales Disability Discrimination Legal Centre to come forward, please. Good morning. Thank you for coming along today. Would you be able to indicate your name, please, and then if you'd like to commence your statement, that would be great.

MS GIVEN (NSW DDLC): Fiona Given, the New South Wales DDLC would like to again emphasise the importance of the National Disability Insurance Scheme to meet Australia's obligations under the UN Convention on the Rights of Persons with Disabilities. We would like to say from the outset that we support a separate NIIS, as this will create uniformity across Australia. We disagree that people with disability should make a co-contribution once they reach the age of 65. The rationale for this is that people with disability would have had less opportunity to accumulate savings over their lifetime.

Furthermore, we disagree with recommendation 4.3 as it further disadvantages people who do not have access to unpaid support. It is our position that there should not be a separation between mental health and disability. Psychology is an allied health service just like allied health service and should be included in the NDIS, it should not fall under mental health as the NDIS is proposing. This is in keeping with the principle that people with a psychosocial disability are classed as having a disability, according to the Disability Discrimination Act 1992 and the CRPD. This is also in keeping with the social model of disability.

The New South Wales DDLC supports the NDIS having a role in achieving accessible public transport as this correlates well with the DDA, Disability Standards for Accessible Public Transport 2002, and also article 9 of the CRPD.

We support people with disability having flexibility and control over their own lives, but some people require your advocacy support to assist them. We are concerned about the lack of reference to advocacy services in your report. Advocacy services are a critical element to enabling people with disability to have control over their own lives. Therefore, there must be adequate funding provision in the NDIS for advocacy services. The report also reads as though people with disability either have the capacity to manage their own supports or they do not, and therefore they have to have someone to manage their supports on their behalf. The Productivity Commission has deferred from Australia's obligations under article 12 of the CRPD as there is no provision for supported decision making. It is our position that the NDIA board and its advisory council should be comprised of a majority of people with disability, people with disability are able to make sound commercial decisions.

We support the creation of an independent statutory officer to review complaints and appeals by people with disability. We support recommendation 7.1.3

to create a specialist arm of the ADT to hear appeals. We also support that there is an appeals mechanism to the courts on errors of law. The New South Wales DDLC supports that the NDIS should have its own legislation. The legislation must include entitlement based support. The legislation must reflect the CRPD. Thank you.

MS SCOTT: Thank you, Fiona.

MR WALSH: Thanks, Fiona.

MS SCOTT: I just wanted to clarify: I think you're after an independent statutory officer to handle complaints within the NDIS, plus the AAT, plus the opportunity to go to courts? Yes, the three levels. Thank you.

MS KAYESS (NSW DDLC):   Sorry, Rosemary Kayess, I'm the chairperson of DDLC. The only dilemma with that is the cost jurisdictions that apply at the various levels of legal appeal.

MR WALSH: I'm sorry, I don't quite understand what you mean, Rosemary.

MS KAYESS (NSW DDLC):   The requirement for legal representation within the ATT and then for appeals in areas of law, the cost jurisdiction at the Federal Court.

MR WALSH: It's the issue of costs?

MS KAYESS (NSW DDLC):   It's an issue of cost; it has potential jurisdiction in issues of cost.

MS SCOTT: You just mentioned it. Are you just saying to us - and accompanying that we reconsider that, are you also saying something about legal representation and costs?

MS KAYESS (NSW DDLC):   The appeals process, once it enters a costs jurisdiction, it has the potential to enter a costs jurisdiction which is problematic for costs in terms of ongoing cost of disability for people with disability.

MR WALSH: I don't quite understand. Maybe we need to break it down a bit. We're talking about a national scheme where, effectively, the cost and liability are held by the NDIA with money funded from Commonwealth consolidated revenue.

MS KAYESS (NSW DDLC):   Including representation?

MR WALSH: That's the issue, I guess. So I think your concern is that if legal representation incurs a cost, then would that cost be met by the NDIA or by other jurisdictions. That's the question you're asking?

MS KAYESS (NSW DDLC): That's the question.

MS SCOTT: Okay. Now I understand. Sorry, it took us a while, but I've got it.

MR WALSH: I guess we haven't considered that.

MS SCOTT: All right. Thank you very much for coming along today. I don't have any further questions. Unless you do?

MR WALSH: I wonder if you've given any thought or consideration to the balance between the overall cost of the scheme, and hence the feasibility of the scheme, with the complexities that might be involved with further representation?

MS KAYESS (NSW DDLC): Again, it's a tricky area because it's a specialised area of law. It's always been the dilemma within the DDA and the various discrimination acts around the countryside. There's a limited number of specialised legal representation available and the cost implication is then not obvious, because you're dealing with a very small pool of both potential people to work with claimants and respondents, and so that can have an effect because of the level that the more specialised representation operates within. So, I don't know, we haven't thought about. I mean, we recognise that because there is a limited pool of legal representation within that area that that could be problematic but we don't know what the implication of that could be. Fiona may have a better idea. Me being the legal academic, her being the person working in a real legal firm.

MR WALSH: I suppose one of the concerns to the commission would be that if legal representation overtakes the operation of the scheme, as it has done in some accident compensation jurisdictions, what you describe as the specialised legal representation which is very well intentioned and I think has a very positive role to play may be overtaken by a much broader legal representation which might compromise the integrity of the scheme.

MS KAYESS (NSW DDLC): One possible way of doing that is that we've got specialised disability discrimination legal centres as part of the implementation of the DDA. There's no reason that they cannot be empowered with that same free legal advice representation for NDIS. The concern is many people don't have access to good legal representation, that their appeal is disadvantaged without the capacity building within the legal fraternity to start with.

MR WALSH: Fiona, did you want to say something.

MS GIVEN (NSW DDLC): I would like to clarify we need both legal and non-legal advocacy.

MS KAYESS (NSW DDLC): But your point of advocacy only gets you so far in an appeals process.

MS SCOTT: Yes. We also probably haven't spent much time thinking about conciliation and mediation as well and in some jurisdictions there's particular focus on that and we have received recently in our inquiries in Melbourne some testimony about the constructive role that mediation can play in trying to reduce overall costs of litigation and so on.

MS KAYESS (NSW DDLC): On a separate note personally, I'm a person who's a recipient of one of the very few structured deeds here in New South Wales and my deed stipulates that I have to go to arbitration rather than seeking an appeals process through court first. Now, that was our instigation, I don't know whether all the deeds have that clause.

MS SCOTT: All right. It's very interesting, thank you.

MR WALSH: You have given us food for thought and that's good.

MS KAYESS (NSW DDLC): One point I would just like to reinforce is that I think that whilst the draft report has indicated that the relationship with CRPD I don't think it has embedded the framework strongly enough.

MR WALSH: Do you have anything to say about the relationship with the CRPD and ICF as a basis for eligibility and assessment?

MS KAYESS (NSW DDLC): Well, CRPD was negotiated within the context that it didn't have a defining definition and that was a painful process, believe me. But it was necessary given the number of member states that wanted to define out certain groups of disability. So the default could always be ICF and ICF has a very broad potential to create a myriad of different types of definitions and eligibility criteria, so it can be a very useful tool. So I think the relationship between CRPD and ICF is not mutually exclusive, I think they can operate very well together.

MS SCOTT: Thank you very much.

MS KAYESS (NSW DDLC): Thank you.

MS SCOTT: We might have a break now and resume in 10 minutes, so that would see us resume at 10 past 11 and when we resume we will be hearing from Frank Peterson.

MS SCOTT: We will now resume and invite to the table Frank Peterson, please. Good morning, Frank. Thank you for coming here today.

MR PETERSON: Just to let you know my name is Frank Peterson and I'm from Hamilton which is located near Newcastle in New South Wales. Thank you very much for allocating me some time here today to let me talk about my experience as a person with a disability. I'd like to talk about the disadvantage that I've faced throughout my life. I'd just like to say how wonderful I think the NDIS scheme is and in allowing this scheme to occur will hopefully alleviate some of the disadvantages and barriers that people with disabilities face. I'm hoping by being able to tell my story today that you will have a better understanding of these challenges that I talk about.

I'd just like to talk about a next door neighbour of mine who is actually a doctor. The story was actually shown on the front page of the local newspaper as he was injured in the Bali bombings. He and a number of other Australian tourists suffered disabilities because of that incident. He was not compensated for this. I'd also like to talk about people that, because of their disability, they also receive issues in terms of finding jobs and would not be covered under the NDIS. He has also made a submission to Mr Anthony Abbott, the opposition leader. He has talked about the pool of funding available under NDIS. There have also been submissions made to Mr Kevin Rudd when he was Prime Minister. The reason those submissions were forwarded is to hopefully ensure the progress of the NDIS.

I'd just like to highlight the fact that both myself and my wife, Ruth, would like to be present when that is tabled at a national level, so when it is tabled in Parliament House. Just talking about two particular areas of disadvantage, the first one being in relation to disability insurance and compensation. I feel that I faced these barriers as I have been unemployed for 17 years. A few years after I became unemployed I became quite anxious about my lack of employment and my prospects for the future, anxious and depressed. I was actually forced to sign a document to state that I was taking retrenchment or redundancy. That was from the Hunter Water Corporation. I had no opportunity, I had no choice and I was suffering severe depression at the time.

I was then forced to go to Centrelink. There was a chaplain, Reverend G. Mainprize who stated that I should be applying for the DSP. There was no encouragement of actually seeking further employment, that I should just apply for the DSP. It was terrible. It was a very confusing time. I did suffer severe depression. It affected my health and it was a few years before I actually felt mentally well again. Prior to my retrenchment I was paying into a private health fund at the top level. When I was retrenched I was unable to continue to do so and I believe there is double standards from the Australian government. I believe that I should be able to remain on a normal salary, as opposed to just receiving the amount that I do on a DSP. According to the law, the standard wage cannot be less when you're transferred from one job to something different. So in effect I feel that I was demoted when I was caused to take DSP compared to the wage that I was on prior to my retrenchment.

However, since that time, I have endeavoured to seek employment. I have tried applying for various jobs, but I thought that my job prospects are quite limited. I was part of the Commonwealth Rehabilitation Services. They forced me into taking employment in a sheltered workshop. It was the house with no steps. So again I feel there's some double standards there in relation to pay issues. I think all employees should be earning the same base wage for doing the same base work. I think there should be no discrimination between those in a sheltered workshop and those in mainstream employment. The wage should be the same.

I have done three various courses since my retrenchment. I've tried to further myself. I have submitted various papers to various government departments, to the Prime Minister, to the ombudsman and I do believe people that have disabilities that do receive redundancies or who are unemployed for whatever reasons should be covered by insurance and compensation. They should be compensated from the date of the redundancy or the date that they were made unemployed. They should be receiving that compensation until they are then in the next paid employment or until they reach retirement age.

People that have disabilities suffer from the loss of benefits, a loss of enjoyment. People who are in employment continue to benefit from these extra benefits, such as superannuation. Just as an example, the employers who pay people that have a disability and pay out their redundancy should ensure that they are paid out until the official retirement age, and that could be covered under disability insurance. People who aren't covered by insurance should be so under the NDIS. They should be paid a minimum wage and their wage should be dependent upon their skills and that should be dated from the date of retrenchment. So they should be reimbursed by the NDIS.

They should be compensated. So the difference between the date of retrenchment until retirement age, they should be compensated for that, or until their death. They should be reimbursed for that balance, either to the date of death or the official retirement age. I'd like to bring this to your attention not for myself personally, but for people out there that have a disability who are suffering those barriers. They suffer barriers and discrimination.

Number 2 is talking about disability insurance allowance. The allowance should be allocated and awarded to people that have disabilities. An example of this might be a deaf person who relies on fax machines or mobile phones for their extra communication needs. Another issue that deaf people might face is they would need to go and travel distances to actually talk to people face to face if they're unable to use the phone. Someone who wasn't deaf would be able to just use the phone to make a call. Again, the barriers do involve extra expenses and can result in discrimination. There are definite disadvantages. Before I close, I do have a copy here of my presentation for both of you.

MS SCOTT: Thank you very much.

MR WALSH: Thank you.

MR PETERSON: I appreciate it. Thank you. Many thanks.

MS SCOTT: Thank you.

MR WALSH: Thanks very much, Frank. Taking your second point first about the communication aids and expenses incurred because of your disability, thanks for that and we'll have a look at the report, but I think we do say in the report that those things will be covered under the NDIS. So I think we can give you some comfort from that point of view. In terms of your retrenchment and removal from employment, we've tried to put a lot in the report around support for realising the potential of people with a disability. So I think under the NDIS we'd be looking to opportunities for you to continue in employment. That's certainly - - -

MR PETERSON: I've already been unemployed for 17 years. I feel I've suffered loss in that time. The pension really makes it very difficult to live a happy and enjoyable life. Obviously you are quite stuck, you are very limited in terms of what you can do and that level of enjoyment that you can experience.

MR WALSH: I understand that. Unfortunately it's not within our terms of reference to look at income support, which I think is what you're talking about in that area. We're looking more at the support needs in terms of what people need; in your case, communication aids and assistance to get back into employment. Actual income support is beyond our terms of reference.

MR PETERSON: I've actually had an ongoing battle with my previous employer over some compensation and they've just said, you know, "Bad luck, we don't care." There needs to be some law out there.

MS SCOTT: We hear that you feel you've been done injustice and I guess it is that the NDIS can't solve every injustice.

MR WALSH: It's good that you've got your story on the public record, Frank. That will be read by people and politicians, so I think it's really good that we've given the opportunity for you to tell your story. Is there anything else that you'd like to put on the record?

MR PETERSON: No, that's it.

MS SCOTT: Thank you very much for coming here today.

MS SCOTT: Thank you, Michael.

MR HERDMAN: Yes. Good morning, we meet again.

MS SCOTT: Just for the record, Michael, just state your name and you're representing yourself, aren't you?

MR HERDMAN: Yes, I am. My name is Michael Herdman.

MS SCOTT: Please, when you're ready.

MR HERDMAN: Yes. Right. When you're ready, madam chairwoman, I'm ready to commence.

MS SCOTT: Please proceed.

MR HERDMAN: I mentioned in my submission dated 23 March that I wish to clarify my position as far as the Australia's treatment of asylum seekers in mandatory detention is concerned, because I do have some information for you about that; I base it on an ALP report.

MS SCOTT: Right.

MR HERDMAN: Basically, with the reaction of the Keating Labor government, back in 1992, the Keating government introduced a form of mandatory detention. As the commission would be aware, in 1951 the UN introduced the convention in regards to the protection of refugees. Subsequent to this, this particular convention was ratified by the Australian government back in 1973 and then subsequently, when the Howard government was elected in 1996, they tried to change detention back again to the way it was before the past few elections of the Keating government. Subsequently what happened was, as far as the Howard government was concerned, they wanted to apply the rights of the list to apply with the Immigration Act only and totally ignore the UN convention on the protection of refugees.

MS SCOTT: Michael, can you relate that to the inquiry we're looking at, which is about disabilities?

MR HERDMAN: Yes. I'm most concerned that, if people will continue in mandatory detention, they will acquire medical problems and also possibly severe intellectual disability. That's why it relates to the inquiry.

MS SCOTT: Got you.

MR HERDMAN: That concludes my first portion of my evidence. I've also been in touch with my local federal member on 9 March. As far as he is concerned and as far the federal opposition is concerned - right, so the last lot of submissions for this inquiry is that you don't go far enough. This is no reflection on your performance or no criticism of you. This is what my federal member observed and also what the federal opposition observed. So as far as they were concerned, the last lot of submissions left a hard edge.

Subsequently, I recommend a cut of 25 per cent amount (indistinct) our parliamentary cycles. I also would submit, as far as our state governments are concerned, conservative administrations, two governments of Australia are conservative, three if you count New South Wales: the governments of WA, Victoria, and more or less New South Wales. As far as New South Wales is concerned, they should suffer a 25 per cent (indistinct) next to all parliamentary cycles and as far as WA and Victoria are concerned, they should just have a three-year cycle, they should limit their funding, as far as they're concerned, if they refuse to comply with the National Disability Insurance scheme. My concern at this moment is the implementation of the National Insurance scheme and that is all I'm concerned about.

To the commission and all the people gathered here, I'm not here to enter any contest as far as conservative governments are concerned, I'm here to do a job, plain and simple. Thank you very much for your attention and your time.

MS SCOTT: Thank you. That's great. Thanks, Michael.

MR WALSH: Thanks, Michael.

MR HERDMAN: Any questions?

MS SCOTT: I don't think so.

MR WALSH: No, that was very clear, thank you, Michael.

MS SCOTT: Thanks for coming along today. I think that draws, now, to a close, our hearing today in Sydney. We'll be now resuming our hearings tomorrow morning at 9 o'clock. Thank you.

AT 11.41 AM THE INQUIRY WAS ADJOURNED UNTIL
FRIDAY, 15 APRIL 2011