

THE PARLIAMENTARY JOINT STANDING COMMITTEE ON COMMUNITY DEVELOPMENT MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART ON TUESDAY, 20 MAY 2008.

INQUIRY INTO THE PROVISION OF ASSISTIVE TECHNOLOGY AND EQUIPMENT FOR PEOPLE WITH DISABILITIES

Mr PETER NUTE, COMMUNITY-BASED SUPPORT SOUTH INC., AND **Mrs MARY GUY** WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

DEPUTY CHAIR (Ms Ritchie) - I would like to welcome you both and thank you for giving us your time to give evidence to the joint House committee on community development, and in particular as it pertains to one of the terms of reference that we have before us. I presume you have had a chance to have a look at those. Would you like to give us a brief overview, Peter?

Mr NUTE - I would like to speak to our submission and then answer questions, if that is okay. I guess we have covered a lot of the issues. The main thing that we, as an organisation, are dealing with is the largely unmet need for items of equipment that are of relatively small value and often not considered in the provision of equipment, so we supply things that you wouldn't normally expect to see. For example, if someone needs support to do their vacuuming, the real issue might be that, due to poverty and other circumstances, they have an old vacuum cleaner that is a great big, heavy model and they can't use it, so typically we have been sending someone in to do the cleaning. That may not be what is needed at all; it might be a lot better for that person to continue doing that job and supply them with a lighter vacuum cleaner. After someone goes three times to do that cleaning, it has been paid for, so it seems crazy to me that we would go on supplying support services endlessly to meet what is a fairly low-level need. With some support sometimes it is easier to just sort those things out and have them remain more independent, so we are looking at other than the standard means towards independence.

The problem we have in doing those kinds of things - and that is just one example, and probably not the best - is that they are not supported by any system. There's no way in which the current Home and Community Care system allows that to occur. The Home and Community Care system measures the number of hours of support you supply, so the way it works is that you do an assessment - 'You poor darling, you need this job done'. It is almost a patronising system that says, 'You have deficits, let's plug those deficits and, surprisingly, you may become more dependent and less independent over time because someone is doing things for you that you might be able to continue doing yourself, with some training and assistance to do it more efficiently or in a less damaging way, or maybe you need some little bits and pieces of equipment'. Some of them are quite simple things such as a slight change of lifestyle, but that is not really a task that is currently measured under the system. Small-level assistive devices that are very low-tech can make quite a huge difference to people's lives; rather than see them go into a spiral of decline because they do less, the potential is there for people to rebuild confidence and capacity and move forward in that way.

But it is not a measurable system; the HACCC system and Disability Services don't have measurements for these things. So not being measurable is not an outcome, but just because we are not measuring anything doesn't mean that nothing is going on.

Mrs BUTLER - Are you saying there's no baseline there, Peter?

Mr NUTE - No, there isn't. What happens is that we do assessments - and those are fair assessments based on tools that have been developed over a long time - but it tends to be that you just fill a deficit: 'You can't do this, so we'll assist by doing this for you. If some small change to your home environment or some small piece of equipment were able to assist you, maybe with a bit of training you could continue to do that yourself?' The cost of doing it that way is much lower, but you have also maintained your independence and fitness. You are more likely to get out of the house more if you maintain your underlying fitness. The problem with the current system is that you tend to sit more, and if you sit more you become less fit, less strong, less able to do all the other things and less able to connect with the community.

We have been inadvertently contributing to a downward spiral and it is but for the insertion of some other types of support, which are more difficult to measure. You can measure the number of hours we supply in support - that's an easy, direct measurement. Then we put that into the system and off it goes to the data repository and everybody is happy, but there's one problem - people become more and more dependent over time.

Mary and I have come to talk about quite different things in some ways because in that sense I am talking about those low-level things which might make a difference to a lot of people, but those who have capacities to regain. On the other hand, if you have a disability that might preclude you from undertaking those kinds of tasks, those things are not going to do anything at all. It is much more important that you have a really good support system and larger pieces of equipment that efficiently do the job and work for you.

The other thing I wanted to raise before the committee - and I am sure it has come up through other things, including the Treasurer's committee on demographic change - is that we are going to run out of staff anyway to do the things the way we are doing them now. I have been looking at that change and a contraction has already occurred. This is the first year that there has been a contraction in Tasmania's work force, but that is going to increase over time as we get more and more people getting older. There is about a 4 per cent per annum increase in our client base at the same time as there is a decrease in the total work force.

Other areas of work attract workers more readily than ours. It is low paid and is not traditionally well regarded, although the people who work in it enjoy the work. So there is that kind of issue about where the staff will come from as the client numbers go on growing. Some people think you can just throw more funding at it but that won't do the job because people still prefer to work in other areas that have better societal recognition than our work. So recognising that as a reality, we have to start moving towards another way of doing things, and assistive devices provides one of those means. There are others, including improvement of diet and the use of occupational therapists to assist people to live healthier lifestyles one way or another, or to do their tasks better.

This is certainly one of those important things, and although I knew this committee was particularly focused on the Community Equipment Scheme, this isn't really about that necessarily. It's an important aspect for the committee to bear in mind, whether or not you are able to do much about it, but I am hoping that at some stage maybe there will be some kind of recommendation or note in your final conclusions that get people thinking in more innovative ways. I think that's all I need to say.

Ms GUY - He said to pass it to me to tell him to shut up.

Members laughing.

DEPUTY CHAIR - I think you are on, Mary.

Ms PUTT - Just before we hear from Ms Guy, Peter, you said that measuring outcomes wouldn't give you that sort of qualitative result about somebody maybe being able to do that job with the right vacuum cleaner, for example, to be more independent and remain more active. Does that mean that we need to incorporate some sort of measure like that to do with independence and activity, but heavily qualified, I suppose, by the person? What I'm trying to wrestle with in my mind is what the actual person getting the assistance wants, and what they see as their need.

Mr NUTE - Actually, I am going to take an odd view on that one. I don't think it's going to matter much what they want in the long run, because if we don't have the staff to send, we're going to have to prioritise those people who cannot do without a personally-delivered service. There has been a lot of emphasis on what the client might want, and that's okay when you've got the labour force to deliver it - or if you even have the financial resources to deliver it, which we also don't have - but if you don't have the people to do it then you're going to have to work the other way. I don't think there's a choice; the question to me is how we are going to measure those outcomes.

My organisation has currently received some money from the Home and Community Care program to look at a trial on assistive devices to actually measure the relative efficacy of one approach over the other. That will assist a bit, but we write contracts that say we will deliver x hours of this and x hours of that. It is probably not the smartest way to run things. The way we need to run it of course takes a lot more assessment and a lot more input, and many fewer person-hours and some equipment that people have trained in the use of, and then monitoring afterwards to make sure it works.

That is probably a deliverable system because it also hits the other end of the labour market that says people want better-paid, more skilful jobs that are more meaningful to them. So at the same time as reducing total staffing, and having more people being independent, the workers in the field are actually doing the higher-order functions, which is the kind of thing people want to do. So when people ask them, 'What's your job?', they can say, 'I'm not a support worker, I'm an occupational therapy assistant', or something like that. The jobs that hit at that end also attract people in the labour market, so we're trying to take an overview.

I think the question of choice will be a misnomer in the future; it is still relevant now but I think in the future there's just not going to be the people.

DEPUTY CHAIR - I am just mindful of the time, so we might let Mary say her piece, and then members can put questions to both Mary and Peter afterwards.

Ms GUY - I guess I agree with Peter on most issues. We've been talking about assistive technology and equipment for years, but I am coming from probably a little bit more practical experience from knowing what it's like to want to do something yourself, not someone else. With a lot of the equipment that I use, I don't particularly like adaptive equipment because you're always running into trouble with that. If you change a particular thing to be used in a different way, often you run into so many technical problems that it creates problems that people cannot solve. It is like putting a bandaid on something. So I agree with Peter. My concern now is that it is going to become increasingly difficult to get people working in the sector. I know that now from having difficulty getting people who want to work the hours you want them to work. I guess 'want' is probably misuse of a word. It is basically for people to be able to live a reasonably independent life. The equipment they have is what they need, not what they want. There are a lot of things, I am sure, that every one of you would like and want but if you cannot afford them, you cannot afford them. That applies to people who are getting older and it also applies to people with disabilities. But if it is equipment that you need to be able to live a life and to be as independent as possible -

My house is set up with a wireless system so that I can press that button - but hopefully not from here - and my front door opens so I can get in and out. If I had to, as I did in the past, wait around for someone to come to go out and come in, it meant I was waiting on human resources. That costs money. It also is an invasion. There are times when you want to just do what you want to do. I can now decide that I am going wherever. This used to be my favourite haunt many years ago and I could come and harass politicians. But I did not have those facilities then and I had to do it the hard way. But you invent things that will work for you, and I think that is where we break down.

We do not look at what is possible, what is not overly expensive but how much does it save in human resources, where we can send someone out to support someone who cannot get out of bed, cannot go to the toilet on their own, cannot get dressed and cannot get undressed and cannot go to bed. Those services are vital. I personally could not survive without another human being doing those things at different times of the day and at the times that I like it done and like to be able to get up. But to be able to do those things, having to have a human resource is vital for me.

Many of the other things I do and I am totally paralysed, I can do with other types of equipment. Most of it is - you imagine it and you think what you can use and what could you have adapted. I was just reminding Peter that I use a thing called a typing stick. It was invented by the Americans about 50 years ago to use on old-fashioned typewriters to type by mouth. My poor old stick has been used for a lot of other purposes than that, including opening and shutting sliding doors and things like that, so I can get in and out other parts of the house. It is just a simple piece of metal that is wearing out and I asked Peter to ask a friend of his if he could have a look at it and see if there is any chance of him making one, not to replace mine because I want to keep it, but to give me a second one, so that if I happen to break the other one I am not stuck because I am stuck without it. I have been without it for a week and I find it is difficult. I did not realise I used it for so many things, even pulling something across the table.

Until you cannot do something you never think how restrictive it is. We assess people and send them in because they cannot do this and they cannot do that and they cannot maybe get certain types of clothing on that could be adapted to equipment, not just your hands. Your hands are very important, I would not put them down, but there are an awful lot of things you can do without them if you want an independent life. I think the independence is probably one of the most important things missing off the terms of reference here. I know National HACC is now starting to talk about it after all these years and they want to see many of their clients being led towards independence after teaching them very well for very many years how to be dependent. We are very good at teaching people how to be dependent but we are not so good at standing back and enabling people to do the things that they could do. Maybe it is a little bit harder to do things but you need to be able to do things to be a person as well. If you cannot maybe pick up certain things there are ways of getting around that. Many people hold onto that dependence for a very long time which can damage them as well whereas maybe we can fix them up with solutions and fund those solutions. If somebody could not get out of bed without assistance and you come up with some way of being able to do that, then you are able put it down in an HACC or disability report as an outcome. Of course it is an outcome. It is an outcome for the person. It is giving back that person their dignity, the feeling that they are of value. Everything changes. We have to accept that there are things we can do and cannot do and that we have to change the way we do them.

Mr WHITELEY - I suppose the other important point there is that it frees up human resource to be used somewhere else.

Ms GUY - That is right. The one or two or three items of equipment pay for themselves very quickly in the sense that you are not paying wages for a person to come in and spend an hour just to be there with someone to enable them to get in and out of their house, to do certain things, or to encourage people to go back to doing the things that they used to do. There are many other ways of doing it in this day. We are backwards in some ways but not that way.

Mr NUTE - If I could make a comment on that just to exemplify it, and I would not use a name, obviously. We have a client for whom an independent support package at the higher level is provided. We looked at the tasks that we undertake for that client and every one of those tasks could be done by that person themselves with the right kind of assistive devices, and we are not talking about any of those being expensive. That person could actually live an independent life now but for the fact that we cannot currently supply the necessary things because it does not fit within some guidelines. The person may not want to agree to all of those things, either, which gets back to that question you had before of choice; but there may not, in future, be choice. I think that is not so much of a relevant thing if you think that people coming into a service for the first time will not have experienced the other way and it becomes the new paradigm.

DEPUTY CHAIR - Can I open questions up to members, with Mr Best leading off first.

Mr BEST - I have four or five questions and I will try to get through them as quickly as I can. You mentioned at the start that after three times with the vacuum cleaning - and I know you said that was maybe a poor example but still a good example, I think, in some ways - that after three times of use it pays for itself.

Mr NUTE - And why would that be?

Mr BEST - Yes.

Mr NUTE - You can buy a vacuum cleaner for about \$89 to \$99. A person going to someone's house costs about \$30-odd. It is a pretty simple sum. If you are having to go to that house once a week, an average client for two-and-a-half years -

Mr BEST - I see, a vacuum cleaner that someone can use as opposed to -

Mr WHITELEY - You would pay for it in a month.

Mr NUTE - That is right, and they are very light. The other thing about the modern ones is there is a little unit that clips on the side that takes most of the particulate matter out and they are at the level that the person can empty. We also have a problem in Australia with the Building Code of Australia- and there are a whole lot of stupid things about the building code. One of the sillier things that we do, and it is not in the code but it is a matter of practice, is that power points are usually on skirting boards in Australia. It is one of the few countries that does such a stupid thing. We cannot rewire the houses; most would cost a lot of money to rewire to put the power points higher up, but you can buy little power boards with a surge control mechanism and they just clip onto a couple of screws further up the wall. You do that, put the new vacuum cleaner in, give a little bit of training on its use and maybe the total investment in terms of money might be of the order of \$300 to \$400, but that person then continues doing that job.

Mr WHITELEY - Thirty bucks a visit.

Mr NUTE - Now, you are then talking 10 weeks it equalises. People tend to be with us, on average, about two-and-a-half years if you look at it from that point of view. This is not an answer for everybody, it is just an answer for those people that that it would work for.

Mr BEST - That is fine.

Mr WHITELEY - It is the principle that you are talking about.

Mr NUTE - Yes. And the principle pretty much applies. We are doing the research right now that will elucidate that much more but other studies have been done. Moreton Council study in Victoria is probably the best example of that.

Mr BEST - Moreton?

Mr NUTE - Moreton Council in Victoria. The principal person doing it was a person called Meg Henderson, she is now in HACC Victoria and that is available, I think, on a web site. So one way or another, you can always contact Meg Henderson in HACC Victoria and get hold of that stuff.

Mr BEST - I am sorry if I am trying to hurry, but it is just that I do not want to hog the situation when other people have questions. With your diagnosis of what can be used

to make life easier for clients, a lot of that is just simply on demand, isn't it? You don't go in and sort of brainstorm about how to do it. A lot of it is about someone having an issue in that they cannot vacuum, for example, or there could be something else like not being able to open the front door back door. Is that is where you diagnose how you can make lifestyle better?

Mr NUTE - It is not quite that simple. We have a standard assessment tool but for this kind of thing we go in knowing a whole lot of other possibilities and we talk to the person about how they would like to do that, not just what we reckon is a good idea. So we engage the person in that and there may be at times potential for some adaptive technologies and we have the capacity in our organisation, but not really generally enough to make some adaptations. But I agree with Mary: adaptations tend to have failure rates, so it is usually better if you can buy stuff. But just to make that clear, we are talking about the Community Equipment Scheme. The Community Equipment Scheme or the people attached to it - the occupational therapists - have been handing out shoehorns for a long time to people who cannot bend over. I think that it is usually metal, it is about that long, and it costs \$12.50. But there is actually one that is a lot better at IKEA; it is that long, it has a grip much further down, costs \$2.95 but they cannot buy it because of the arrangements of trying to get stuff out of IKEA by government. There are a lot of rigidities in the system that are really stupid. If you were a private individual you would never have that happen.

Mr BEST - I know what you mean; I have seen those catalogues and you can have a bit of a laugh at times at some of the crazy stuff in there but there are some good things.

Mr NUTE - Innovations. You have this little thing you just put on top of a can and it takes the thing off safely. This is not just for people with a disability, this is you and me, and because it is you and me those Innovations catalogues have beautiful things and every time we see stuff like that we buy a few for our program because they are so cheap and we can afford to have a few spare and not even use them - they will eventually get used.

Mr BEST - Mary, you mentioned the importance of independence and you said how difficult it was, some years ago, lobby up here around Parliament because of other restrictions such as opening of doors and so forth. If I could just take you back then, in your mind what do you think your percentage of independence was? I do not know if that is a good question; should I say, rather, the struggle for independence perhaps? How would you rate that percentage-wise in comparison to now? I will get to the next question in a minute. Just out of interest, what was available going back to a time when you could not really do a lot?

Ms GUY - When I first started visiting Parliament House, the Legislative Council and all the offices and departments in between, it was actually not acceptable for a person in a wheelchair to dare to front places like Parliament House. I am talking 25 to 30 years ago. To bail up a politician out the front and demand access to Parliament House, to get inside they would have to go and find three or four of their colleagues to lift the wheelchair into the building. So the lack of dignity alone was bad enough. The difference between then and now is that I now lead a reasonably independent life. I go where I want, like anybody else, within your own resources, when you can afford

or get a cab, that type of thing. So my level of personal independence is huge compared to that. I do not know how you would rate it.

Mr BEST - But you are saying it is attitude and technology, in a way?

Ms GUY - Very much so, yes. Even politicians do not like bad backs.

Mr BEST - Where do you think it could go, then? If things continued to move in the right direction, what is possible, do you think?

Ms GUY - Pretty well anything that anybody really wants, and I do not think the disability or the ageing process really affects that. It is how people really want to continue to live and how they are willing to change their attitudes and perceptions of what they knew 10, 15 or 20 years ago, against now.

Mr NUTE - What about getting into here today?

Ms GUY - Today was bad.

Mr BEST - I thought it would be - to get up here in particular.

Mr NUTE - This is terrible.

Mr BEST - It is much worse than the other section.

Ms GUY - Yes. My experience of entering this building had been a lot better in the last few years. I knew all your back corridors. I used to be able to get from Parliament House to the Legislative Council, out through the old Health building and I knew all the back corridors - and I was taught then by premiers, not by people who worked in the building. Well, I suppose they worked in the building.

Mr WHITELEY - Some would dispute that.

Ms GUY - The attitudinal change is huge and that helps. It also helps if people with disabilities in particular are much better educated. I guess our ageing population now is also better educated because they are coming from a better educated environment, but people with disabilities in particular are better educated. Some of them have had a life where they have supposedly entered the mainstream community, but it is nowhere near where it should be. But to enable people, once you get a feeling that you can do that and you can do it on your own, you are going to want to do it on your own and then make the choice of who comes with you.

Mr BEST - Finally - and I will not ask any more questions, but let other committee members have their go - just a quick one about innovation. I am interested because you have explained to me, and I appreciate that, how you work with somebody to find out what their needs are. You talked about the fact that there are things out there that you do not really think of and then, all of a sudden, someone will find something in a catalogue. Do you think that there could be any benefit - and I am not sure whether it would be statewide or in a regional area - where you might have some kind of innovation committee made up of people from disability groups, meeting and looking at products

and asking for ideas and things like that? Or do you think we should just let it evolve as it is? How could you improve upon identifying what you term as cheap, useable things to make people's lives better?

Mr NUTE - There is a quick, long answer and that is the Independent Living Centre. They are good - I am not knocking what they do - but they do not look for the everyday things. The problem is that they have all the wheelchairs, commodes and all that kind of equipment, but they do not have the bits and pieces that you would get from the Innovations catalogue or something.

I think you are probably right; there is probably room for some kind of improved data repository constructed by one means or another. It could be little things, for example, a lot of people cannot clean their showers and bathrooms, but in fact there is a product that Moreton Council found called Shower Sparkle that is environmentally friendly - that was one of their criteria - as well as highly effective. As long as you can use your hands you can spray it on and leave it, because the next time you have a shower it cleans it.

Ms PUTT - I need that!

Mr NUTE - Well, everyone at my work is using it because it is a damn sight better than scrubbing away at it, because we have non-skid vinyl and it's a bit crinkly and you are constantly at it. Since we have started using that product it is no effort at all.

Ms GUY - Just adding to that, Peter said 'as long as you can use your hands', but there are adaptive pieces of equipment that can be added to that sort of equipment, as long as you can aim the bottle in the right direction. It is about getting together, sitting down and thinking about the ways you would do things.

Mr NUTE - That would be very valuable and it would be more valuable if it had some kind of status than if Peter Nute from Community Based Support did it, because there's all that stuff about egos et cetera, so if you set some other independent body, people who otherwise might not as readily talk to each other can be asked and then they will all join. It's just the way we are; it's human reality. But I think that is a really good suggestion and I would encourage that idea.

Ms PUTT - My first question follows on from all of this. Would it be correct for me to say that a problem we have at the moment in relation to equipment is rigidity of thinking and rigidity of the way funding flows, dependent on a perceived hierarchy of need and on which equipment can attract funding, whereas what we really need is flexibility in relation to individual circumstances?

Mr NUTE - Yes.

Ms PUTT - I guess this is more for the committee but also for you: would it be correct to say that in order to have that flexibility, what needs to be removed is the cut-off point for money, otherwise you're potentially not going to get there - or is that not related?

Mr NUTE - It's not quite that simple. The difficulty is that we really need to show that the outcome has a value and that we can still meet audit requirements and all those kinds of things. It is about governance of programs in a lot of ways. There is an inability in a lot

of ways to measure that. The problem is measurement and meeting contracts - how do we reframe those contracts? - and it is a challenge. There are a lot of other things that go with it because if we started working that way, the work for our staff would be less regular. It would put a lot more highs and lows into their work. We would then need to employ our staff on a much more regular basis in order to overcome the issues that would arise from casual employment in such a scene. If you are helping someone a lot for a short period and then you are off quickly, how do you get the staff to cooperate in that process of downgrading their own work? I think there is a lot to be considered.

Dr Matthew Parsons from the Health department - or it might be the university - in New Zealand has examined that question. He is going to be speaking at the Home and Community Care conference in Hobart in November, so that might be an interesting thing to follow up. He has addressed all those issues and they have looked at them in fairly great detail in New Zealand in, I think, the Wellington area.

Ms PUTT - My other question was in relation to waiting lists and multifocal assessment. In your submission you say that clients would often benefit from multifocal assessment/case conferences but these are often precluded by lack of resources. Could you give us a bit of a snapshot of that?

Mr NUTE - That's easy - there are not enough community occupational therapists. They are in very short supply, as are physiotherapists. Tasmania is doubly disadvantaged because there is no OT school at the Tasmanian university. I think it is a really important, urgent issue because with the 4 per cent increase in the number of clients every year we have this crying need and no school, and what happens typically is that a batch of students will come down, do their training at the hospital or wherever, and while the cohort stays intact they tend to all stay, but when one goes off then a whole lot of the others disappear, unless they've got partners locally - but then maybe the partner goes too, so there tends to be a real difficulty. Now if you train local people, sure, we've got a typical bleed-away in Tasmania - that's one of the reasons we have a labour problem in Tasmania - but nevertheless, there's more likelihood of return and more likelihood of them staying if we have local people. Besides, there's a national shortage anyway; Tasmania's just the worst case. If nothing else were to come of this, to get an occupational therapy school at the University of Tasmania is essential and it can't be left any longer. It has to be set up as soon as possible because we can't do these assessments without them.

Ms PUTT - Just to understand about the assessments, would they typically take place in the client's home?

Mr NUTE - Oh, yes. That's kind of the opposite of some of the stuff currently happening in Home and Community Care where there's more emphasis on phone work. This is saying that we probably need to be going in the opposite direction.

DEPUTY CHAIR - The last question to Mr Finch.

Mr FINCH - That was actually getting on to the question I was going to ask. You mentioned in your report, Peter, about multifocal assessment and case conferences. How do they work now and what do you see would be beneficial for the operation in the future? Can you touch on that?

Mr NUTE - They mostly don't occur now, so that's number one. Where they do occur and are very successful is in the hospital, where the specialist gets everybody together. They've got the imprimatur to do it, so that happens. It is typical of our worship of the medical profession in this country that whatever they say, everyone will do. I wish it were the same for other areas - you've probably wished the same for politicians.

DEPUTY CHAIR - No.

Mr BEST - Dr Finch.

Laughter.

Mr NUTE - The problem is that they occur really well out of, say, the Dwyer Ward, and then all kinds of things can be put in place and it's great. But outside of that, it's virtually non-existent. It may not always be necessary, it's just that where it is a good idea, we still can't make it happen.

Mr WHITELEY - Not that I need to defend the hospital, but I suppose practically it becomes more attainable, doesn't it? They are passing each other's doors, and everything, so it's a practical issue as much as anything, and I think we could do a lot to rectify that.

Mr NUTE - And when they call us in we'll go.

Mr WHITELEY - That's it - yes.

Ms GUY - I know this committee came out of matters of concern about the CES and the restrictions and all the rest of it, and people waiting for wheelchairs for four or five years. I'll bet you I get more phone calls asking to advocate for children who are totally paralysed, cannot get around and have been told they are on a waiting list for five years. The need on the CES side has got to a disgusting stage. That is my own personal opinion; it is very poor. This is essential equipment. I don't see the provision of an electric wheelchair or a wheelchair as being generous to people with disabilities. It's like telling people in your position that for the next five years you will walk around but with nothing on your feet at all, and you'll walk over the cobblestones out the front. You can still walk, whereas the majority of people waiting for those chairs can't move. Without my chair, I would have none of what Mr Best was talking about - the independence, the whole thing. The chair gave me the chance after many years, 22 years, of being able to move on my own.

DEPUTY CHAIR - On that note, I think it is probably a good one to finish up with this particular evidence, so thank you both very much for coming in.

THE WITNESSES WITHDREW.

Ms MARGARET REYNOLDS, STATE MANAGER, NATIONAL DISABILITY SERVICES AND **Ms ROBYN WILKINSON** WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

DEPUTY CHAIR (Ms Ritchie) - Thank you both for coming. I am sorry we are running a little bit over time. The format normally for our committees is witnesses can speak to their submissions and any other matters they would like to raise today and members will capably ask questions afterwards. Please feel relaxed and if either of you just start and we will direct our questions when you have concluded.

Ms REYNOLDS - Thank you very much. My colleague, Robyn, and I prepared this paper although Robyn had much greater input than I did. I wanted to start off by outlining very, very briefly the view of National Disability Services Tasmania and you have already heard from some of our members, I think - the Independent Living Centre, St Giles, Anglicare, Tas Deaf I think -

Mr WHITELEY - Not yet.

Ms REYNOLDS - The recommendations are trying to look specifically at the Community Equipment Scheme as it is at the moment and where we think it should be heading. It is a fairly generic submission; we have not gone into a great deal of detail about the specifics of which equipment, and the nature of which equipment is better, but it is about a better-functioning scheme because the members of NDS have found that there has been inadequate funding and what funding there is has been directed primarily to medical rehabilitation. Far be it for me to say that that is not important. That is an absolute priority and I hope our submission does not in any way try to divide between the medical and the community but we are concerned with community living. It is very distressing for individuals - and Robyn will talk about that in a moment - and service providers when they cannot enable people to be out there doing the things that they want to be doing. It is government policy to have a community-living framework for people living with disabilities. Without equipment though, the full range of assistive technology, that community living philosophy just is not possible.

We have made a number of recommendations I will not read through them all but I will just summarise. We just feel that the Community Equipment Scheme needs a total overhaul. That is not to say that there are not good things that are being done within the existing scheme but it is not meeting the needs. We need a totally new community-assisted technology scheme and I am very pleased to see this committee adopting that language because a lot of people still think of aids and equipment instead of that broader all-encompassing term 'assistive technology'.

Mr WHITELEY - Your attachment of K.W. McCulloch, it is only half a dozen pages but that is exciting documentation.

Ms REYNOLDS - It is.

Mr WHITELEY - I actually think that we ought to be going to have a look at that.

Ms REYNOLDS - I think you should.

Mr WHITELEY - That looks overwhelmingly positive to me, what they can actually do now with -

Ms REYNOLDS - And government needs to adopt an assisted technology policy so that it is encompassed across all areas of government. I know in one of our budget submissions we challenged government to spend just a small amount of what they are spending on technology across government to put into the disability sector. We did not get any response, but never mind. Of course we need funds. Obviously the scheme has been underfunded. Some people cannot even remember when it was last funded except of course more recently when the minister announced top-up funding. The other point, that I know Robyn will speak about, is that in getting a response to about what kind of equipment is needed you need to ask people themselves. It is not good enough just to rely on the medical profession. With every respect to the medical profession, they are not living the experience of having a particular disability so you need to be involved with people themselves. I think that is all I wanted to say and I will come to KWMC later.

Ms WILKINSON - I would like to get back to some of the basics, that anything that is to do with disability should include people with disabilities in the policy-making decisions. There is no grievance mechanism if you are not satisfied with what has happened, there is nowhere to go. There is no sort of breathing space within it. Whatever you come up with in a new scheme, I would like to see people with disabilities themselves involved in the process. It is absolutely vital because we can bring a different perspective which relates to our personal lives. For me that is really important. I would like to see a scheme that has some policy around it that people with disabilities have had input into and, however it is run, also that input, if you like, from the consumer perspective. And with great respect to occupational therapists who seem to be the main gatekeepers of this stuff, I hope I am not offending anybody,

DEPUTY CHAIR - Don't worry about that.

Laughter.

Ms WILKINSON - I have a great deal of respect for their profession but they do not live with the stuff that we do. For example, I as part of my community work do a lot of travel interstate. I asked for a really simple chair for me to use that could be easily pulled apart and easily put together again. I have a chair that can take the airline an hour to dismantle and two hours to reassemble and it takes two of them to do it and they keep telling me that I should travel with a carer and that my carer should be able to do all this stuff. Can you imagine the frustration every time you get on a plane of worrying whether they have done it properly and how will we get it together again? Just last week it took me over an hour from the gate of the plane down to the baggage carousel to get the chair back together and in its right position. People do not know how to do these things. I admit that I get very edgy but those are the sorts of things that I tried to make clear right at the beginning, yet reality was totally different.

The other thing is, having talked with people with disabilities, sometimes you have to wait so long for the equipment that in actual fact what you get provided with does not necessarily meet your need because you have gone downhill over two-and-a-half years or

whatever. With regard general maintenance, I do not know how many of you really know what happens if you get a piece of equipment. You pay I think, and I might be wrong, \$50 or \$100 hiring fee or whatever it is, but then you are still responsible for maintenance. So even if you have a faulty chair you have to pay an extra \$50 every time you get the maintenance people out. That might seem okay for most people but it is very difficult when you are on a low income anyway. You do not have to buy replacement batteries for your legs. You might for your car but not for your legs.

Mr WHITELEY - That is a good point.

Ms WILKINSON - There are a whole lot of those things. Yes, you buy new shoes, but the cost of the wheel replacements or tyre replacements is enormous for somebody on a very low income. So it is those issues from a consumer point of view. You have a disability, but you have no disability allowance and you are always paying out even just for the basic thing of moving around.

The other thing is that, for somebody like me, there are a whole lot of what would be classed as ordinary household appliances. If I have a washing machine and a dryer I can do my own clothes because I can go from the washing machine to the dryer. If I have to hand it out I cannot do it. So it is those things. I need a bed and, yes, everybody needs a bed, but my bed 10 years ago was \$3 000. I need a replacement bed, it does not last forever, and I do not know how much they are but I do not have that kind of money. What I did do is get a chair that now helps me stand up because I am going downhill. Castles were having a sale and I bought the chair that would normally cost about \$3 000 for \$600, so I thought that was a real bargain.

So, yes, they are everyday household items but they cost a whole lot more than anything else. So you are really asking people who are on very limited income to pay out and pay out for something that is a bit better than usual.

So I make some of those comments from an individual point of view. We are always told there is not enough money and that there is a waiting period. But, for example, when I got this chair I would have liked some kind of trust fund that was annually receiving \$2 000 or \$3 000 for the next chair which I need now, that I might have to wait two-and-a-half years for. If you cannot go anywhere or your chair is faulty, you really are up shit creek without a paddle. Sorry, I do not know how else to put it.

Laughter.

Ms WILKINSON - Sorry, my language is a bit basic. I would be really happy for all of you to ask questions about these issues.

Mr WHITELEY - I think it is fantastic, Robyn, that you have come to give a practical submission and I want to take that to another level. If you have had something to do with this submission, you are a little bit out there with your thinking and you thought about the options, so you must have thought about the options as they pertain to you. So in basic dollar terms, if an amount of money was to come your way to purchase assistive technology options for you, wheelchairs that can stack up in - do they exist, by the way, those wheelchairs? Is it only a matter of being able to afford them, the ones you need on

the plane? With all the equipment you have can you get a chair designed to open and shut?

Ms WILKINSON - I am sure I could.

Mr WHITELEY - Taking that into account and your dryer and your washing machine, are we talking about a lot of money in your individual case to give you a lot less frustration and a lot more independence, which is obviously going to save the Government money anyway? Have you thought about how much money that would take right now to get you on a firm footing to move forward independently? You are the living example right here with us.

Ms WILKINSON - I think there would be an initial payment of, say, \$20 000; I haven't really researched it, so please forgive me for that. After that, for me it would be the trust fund with about \$3 000-\$5 000 going in every year because that allows for inflation costs and all the rest of it. If I die before my renewable chair date, you have that money in that trust for somebody else, so if we're doing that all the time - I just would really like to find a solution to getting out of the waiting list scenario.

Mr WHITELEY - I suppose that is what I was getting at. Are we talking hundreds of thousands or tens of thousands? As a committee we don't know what that chair costs, we don't know what the dryer and washer combination that you need costs.

Ms WILKINSON - Five years ago this cost \$7 500.

Mr WHITELEY - It is probably \$12 000-\$15 000 by now. And it would last what - three or four years?

Ms WILKINSON - Yes, five years maximum.

Mr WHITELEY - So that's two or three grand a year.

Ms WILKINSON - Some of the more expensive ones might last for 10 years.

Mr WHITELEY - But your needs might change, though.

Ms WILKINSON - Yes, that's the other thing; my needs are changing with ageing. I used to walk and not have to rely on personal care. I used to be totally independent and I would still like to be as independent as possible. I would like to be able to just press a button, hold this down and then the chair is ready to go on the plane, or whatever. That for me would be just brilliant.

Mrs BUTLER - Robyn, do you have a case worker who does some sort of future planning with you? How do you get these things going?

Ms WILKINSON - You take pot luck. You ring up and hope that somebody might be allocated to you.

Mrs BUTLER - Really? Who do you ring up?

Ms REYNOLDS - I know who you don't ring up.

Laughter.

Ms WILKINSON - I guess I would ring the Community Equipment Scheme. I have been doing that because I've had to have repairs done because there are some basic faults in the chair. If I were to ring them tomorrow and say, 'Look, I'm really needing a new chair', I don't know - it would be an OT who would do the assessment and I would either go into the Repat or they would come out to me. Then you try stuff, and you might have three chairs to choose from and you try them for about 10 minutes each, but when you are trying to make a decision about what your needs are, that is really difficult. I was also offered a trailer for the back of my car to put the chair on and they got this huge trailer. I don't know how they thought I would learn to back up with a trailer, because I have never done that, but I also had to be able to get the chair up onto this trailer with one hand, and even the therapists couldn't work out to do it with both hands. So for me, it's those sorts of frustrations. I shouldn't lose my temper and I often do, but when you have it every day of the week, can you understand how it is? I don't know whether any of you ever lose your temper.

Laughter.

Mr WHITELEY - No - never, ever. We're pleased to have someone as unique as you giving evidence.

Ms WILKINSON - I wish I didn't lose my temper and I wish I didn't swear, and all those sorts of things, but -

Mrs BUTLER - So there's no case worker who looks after your life and future planning?

Ms WILKINSON - No.

Mrs BUTLER - Do you think that would be one way of helping or would it be too restrictive?

Ms WILKINSON - It might be. The other thing is you have agencies such as the CES that suddenly ring me up and say, 'Robyn, we've decided you need a seat in the bath'. Again, I wasn't asked about this; this was because a worker had gone in and said they were really concerned about the way I get in and out of the bath. Nobody discussed any of that with me. If that person who came into my home had spoken to me about it I would have said, 'I'll use another method of getting in if you are really worried about that one', so I have been through all this thing with an OT - I have gone around looking at hoists and God knows what - but I don't want a hoist yet. I'm sorry, I just find that too much. So there are all those other things. Sometimes you are almost over-serviced and then at other times you are really under-serviced -

Mr WHITELEY - Or incorrectly serviced.

Ms WILKINSON - You are right, there is no case management or whatever. I would not even mind being my own case manager with a bit of financial advice, because I am not that good with money; it tends to go through my fingers. But if I had that I could

probably manage my own stuff with a little bit of help from people about, say, when I need a new chair, what might be the best one to get.

DEPUTY CHAIR - Okay, last question, Ms Putt.

Ms PUTT - This is just a really elementary one that flowed from what you were saying. I presume that when you get a piece of equipment there is no maintenance budget associated with it.

Ms WILKINSON - No, you pay out for that. No, sorry, you do not pay the true cost of the maintenance but it is \$50 every time I call them up, so I tend not to do it. If things are going wrong you say, 'I'll make it last a bit longer' -

Mr WHITELEY - That is if only they have supplied the chair. We heard evidence that if you raise funds via a community group to buy a chair it has nothing to do with the Community Equipment Scheme and they will not even pick up any of it.

Ms WILKINSON - No, that is right.

Mr WHITELEY - It's your responsibility entirely; that is the reward you get for taking the pressure off the budget.

Ms WILKINSON - You have to find places to go to get things like your batteries tested and your tyres pumped up and all of that sort of stuff. I have one at the moment with tyres that are really bald and if it was a car I would be off the road. For those sorts of things, no, there is nothing for that.

DEPUTY CHAIR - Thank you very much, both of you, for taking the time to come in and speaking to your submissions. We greatly appreciate it and no doubt you will look forward to the report when the committee -

Mr WHITELEY - Is it possible - we can do it ourselves but K.W. McCulloch and you - is there a couple of places we can look at independently in our own electorates?

Ms REYNOLDS - Certainly in Launceston, yes. I would certainly recommend that you go.

Mr WHITELEY - We can talk about that after.

Ms REYNOLDS - Yes, talk to K.W. McCulloch. One of the issues is the privacy of the individuals that is described. The best thing is to make direct contact with K.W. McCulloch. They won our innovations award last year.

Mr WHITELEY - Thank you very much.

Ms PUTT - The part about the socio-remedial situation is so important.

Ms WILKINSON - And you dare not have too much money either or else you have to buy your own equipment, as you say, with all those associated things. So it is actually encouraging dependence and being on the welfare system, really.

Mr FINCH - I hope you don't find yourself up the creek without a wheelchair.

Laughter.

Ms WILKINSON - I probably will.

THE WITNESSES WITHDREW.

Mr PAUL DUNCOMBE, EXECUTIVE OFFICER, TADTAS, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

DEPUTY CHAIR (Ms Ritchie) - Welcome to our committee hearing. Thank you for taking the time to come along. We appreciate it and apologise for the delay. The normal format is for witnesses to speak to their submissions and/or any other issues they want to raise and then members will direct their questions immediately after, and sometimes in between.

Mr DUNCOMBE - I am the Executive Officer of TADTAS, which is an organisation that recruits volunteers - and they are mainly blokes with sheds - to assist people with disabilities by tailor-making things that make their lives easier. Is it appropriate to hand this stuff around?

DEPUTY CHAIR - Yes, absolutely - feel free.

Mr DUNCOMBE - The organisation has been in existence since about 1990 and has been in receipt of State government Disability Services funds since about 2003-04. It is a small amount of funding, \$30 000 a year, but because we're a volunteer-based organisation we don't need much money. We just need an office, a phone and an Internet connection. I am paid for six hours a week, as is our technical coordinator, and we get by.

We make all sorts of things, and maybe if I could pass these around - I would like them back - you can just get a bit of an idea of what sorts of things we have been able to do. We are usually approached by occupational therapists, physiotherapists or medical practitioners, and we try to meet an individual need of an individual person, which I think puts us in a fairly unique part of the whole service to people with disabilities. The medical practitioner is part of our team while that project is under way, so we are tick-tacking with them all the time. We did 44 projects last year and we'd like to be doing 100 a year. Our undertaking with the department is that we will get up to 100, but because we started from a very low base in 2005, it has taken an amazing amount of time for the word to get out that we're out here.

We have very strict quality control measures. Our technical coordinator has a PhD in physics and a very big workshop, both of which seem to qualify him for overseeing all the projects that we do, so we've got good quality assurance processes in place and it's one hell of a buzz, I have to say. It's a great organisation to be with.

Mr WHITELEY - What is the limiting factor from 44 to 100? Did I miss something?

Mr DUNCOMBE - There's no real limiting factor, it's more about people knowing about us and getting the word out there.

Mr WHITELEY - So it's not so much your capacity to deliver as it is making sure people are aware of your services.

Mr DUNCOMBE - Yes, because it doesn't cost much to do those other 60 projects because of the volunteer component there. We only charge our client for the materials that go into it, and our volunteers have big sheds and there's always a bit of something up the

back of the shed, so the material cost is quite small. We've managed to get a sponsorship deal with a few organisations around town, and they either give or sell us material at cost price. We just wave our TADTAS volunteer's card around and the price comes down, so we are able to deliver a very cost-effective product to a wide range of people with a wide range of needs.

Ms PUTT - When people come to you, what's their history like of discovering that you exist and the sort of need that they had before that?

Mr DUNCOMBE - It's usually through a health professional that we are approached. It doesn't have to be, but they are the people who know most about us at this stage, I think. So it is the occupational therapist or physiotherapist who will say, 'Oh, that official product doesn't quite work'. We had one the other week where the footplates on a wheelchair were too small, given the fact that the person had big feet which were constantly bound up in bandages. So we just made an extension to the footplates. It was quite a simple job - I got the volunteer's costs this morning, it was only \$69 - and that person now has a tailor-made modification that suits them.

I used the example of a wheelchair; we do very little work on wheelchairs, to be honest, because that seems to be covered in other areas and I am sure that you found that in taking evidence. So it is not much in wheelchairs but it is innovation. This little girl is almost our mascot now. She, like all little girls, wanted to be on the beach but the walker that she had to use with its narrow wheels just dug into the sand. These are fishing buoys off a fishing net and we just put them on and away we go. So sometimes the solution is very easy and you can make a hell of a difference in a very short time. I guess that our concern with the inquiry that you are undertaking is that we see all that as clicking together. So the Community Equipment Scheme does what it does and then there is community-based support, for example that does house renovations and modifications. We do not do that because they do, and if one bit of that gets shaky then it collapses onto another organisation and we know that we are not qualified to do some of those other things.

Mr WHITELEY - But you are at the innovative end; you are looking for innovative, one-off possible solutions.

Mr DUNCOMBE - Yes. And if another part of that suite of services collapsed we would find ourselves not at the innovative end because we would be sucked into doing the ordinary and our volunteers would lose interest because they come to us because they want to be at the innovative end. We would not knock back the jobs but it just would not work somehow.

Mr FINCH - We heard earlier that the adaptive technology sometimes does not work because it has been adapted from something else. I am really fascinated with the work of TADTAS. What does TADTAS stand for?

Mr DUNCOMBE - It can be what you like.

Laughter.

Mr DUNCOMBE - It used to be technical aid for the disabled and when I joined the organisation I said that I would accept the position if you change the name because of 'the disabled'. I come from a background in the community health sector and -

DEPUTY CHAIR - 'Technically advanced designs', I was thinking.

Mr DUNCOMBE - In Western Australia it is 'Technology Assisting Disability', so the innovation is around that. But we are just called TADTAS.

Mr FINCH - There is a link-up through the various States of Australia is there?

Mr DUNCOMBE - Yes, there is a TAD in each State and Territory and there is an oversighting body which is really a couple of people from each organisation getting together in a confederated way.

Mr WHITELEY - Do you share ideas?

Mr DUNCOMBE - We share ideas and we look at legislative changes, innovations, quality control and safety.

Mr FINCH - I was curious about your operation here in Tasmania. I see your address is Sandy Bay; do you have an outreach to the rest of the State? How do you work?

Mr DUNCOMBE - We do. The office is the front room of my house.

Mr FINCH - So there is no travel time in that six hours.

Mr DUNCOMBE - No travel time involved. We manage to complete projects throughout the State but it so happens that nearly all of our volunteers are in Hobart. We have one in Deloraine which is very handy; that branches out to a few different places. Our volunteers are mostly retired people and they do not mind travelling around so we have done jobs in St Helens, Devonport, Burnie and all over.

Mr FINCH - With the way you are structured and set up, do you draw on the community organisations like Rotary and Lions and such to boost your funds - like your \$30 000 that you get from the Government, did you say?

Mr DUNCOMBE - Yes.

Mr FINCH - Do you get that from a particular department?

Mr DUNCOMBE - We get that from Disability Services.

Mr FINCH - Do you get other support? Are you looking for and seeking other support?

Mr DUNCOMBE - Not really because the \$30 000, even though it is not much, tends to do us.

Mr WHITELEY - Isn't that good to hear.

Mr DUNCOMBE - We got some money from the Anglican Church diocese. Our technical coordinator, Tony, is just a whiz at all sorts of things, and he fixed up the seal for the Bishop. The seal was broken and Tony fixed it because he knew the Bishop's assistant, so they gave us a donation. We have been able to use that for a family that could not afford even the materials. We did the job and the diocese money went into that project. We talk a lot to Rotary clubs because that is part of our strategy to get our word out there but we are not really tapping them for money.

Mrs BUTLER - Kerry touched on a couple of things that I was going to ask you about. I was talking to some people in St Helens who are very keen to do this sort of thing. So will they get in touch with you? They have their own sheds, lots of tools and lots of time and lots of motivation.

Mr DUNCOMBE - Yes. We have a process that we go through but it is not a painful one. We check out their shed for OH&S issues and we get a police check just because they are working with vulnerable people, and there is not much more.

Mrs BUTLER - How do you advertise your services? How do you let people know that you are there?

Mr DUNCOMBE - That has been really tricky because with \$30 000 a year, no advertising budget.

DEPUTY CHAIR - Electorate newsletters people?

Mr DUNCOMBE - Yes, electorate newsletters are good. Duncan Kerr has been good to us, there have been a couple of runs in his newsletter. I do a bit of radio stuff whenever I can, but they do not want you talking about the same thing every week. So when a few months have gone by I wriggle my way into the radio station and do a little talk, but it is not easy.

DEPUTY CHAIR - What room for growth would you see your organisation having if you were suddenly exposed to a lot more advertising and, therefore, client activity coming your way?

Mr DUNCOMBE - We would be very comfortable going to the 100 projects a year, which is double our present capacity. I am thinking that without too much bother and a few more volunteers we could double that again. Then things would start to strain and the six hours a week would not be enough and the office would have to go somewhere else because we would need more people in the office. We would be really happy at 100 and we would be quite comfortable at 150.

Mr FINCH - Is the need there for you to expand do you think?

Mr DUNCOMBE - I think it is because if you look at the range of jobs that we have done, it is so diverse. Someone wants something on their wheelchair and someone else wants something in their bath and someone else wants something - and we have a smoking aid there. That person had about six weeks to live so we did not think Quit, we thought we would just build the smoking aid.

Mr WHITELEY - There are probably people sitting at home with day-to-day challenges but unless they have seen an innovation in the IKEA catalogue or whatever, they probably would not even think of asking about it. But if you were out there promoting it they might inquire. The sort of people I imagine you have working for you love the challenge.

Mr DUNCOMBE - Oh yes.

Mr WHITELEY - So it is more like, I need this thing to do this function and is there any way you could design it. It is research and development as much as anything isn't it? I do not know the people you have involved, but I imagine the greater the challenge, the greater the excitement?

Mr DUNCOMBE - Oh yes, very much so and our technical coordinator, Tony, is the original lateral thinker. An OT will come along and say, 'We want a widget to do this' and he will say, 'No, no', and what we finish up with is something that goes a different way altogether.

DEPUTY CHAIR - Can I ask you, how does your organisation operate in terms of coverage, liability and those issues, for what you develop?

Mr DUNCOMBE - Yes. We have product liability and we have volunteer liability cover.

DEPUTY CHAIR - Which presumably is all covered with the \$30 000?

Mr DUNCOMBE - Yes. In a previous life I managed to find a very good insurance broker who knows the community sector very well. So I went back to him and he stitched up a really good deal for us for \$2 000 a year.

DEPUTY CHAIR - Does that cover someone injuring themselves because something that you developed for them breaks?

Mr DUNCOMBE - Yes. We renewed the policy this week and \$1 700 a year.

Mr WHITELEY - Have you had any problems?

Mr DUNCOMBE - No we have not had any problems but that is what you have insurance for.

Mr BEST - On that matter of linking of information, and you are about coming up with ideas to solve things for people, we heard already this morning that there could be some interesting innovations. Do you see the outreach of information? You are not someone with a disability I am assuming.

Mr DUNCOMBE - No.

Mr BEST - But you are someone who is a provider so do you see that maybe the outreach of information as to where assistance can be canvassed or options of assistance could be better?

Mr DUNCOMBE - Yes. If there was a good mechanism for publicising things that can help people with disabilities, we'd be there knocking on their door. We'd say, 'Put us on your list. Put us into that system'.

Mr BEST - You don't have any ideas of how that could be improved upon?

Mr DUNCOMBE - No. We tend to go to every expo there is for people with disabilities. We've tried working with the professional organisations, the OTs and the physiotherapists associations. When you think about it, we need to know something when we need to know it. If you hear about something this week and you don't need to know it, then something comes along and in two months' time you say, 'Oh, there was something, but it's gone'.

Mr BEST - I am going to ask a question that I probably should know the answer to. You have a web site here - tas.org.au - are you aware of any comprehensive web site you could go to and see the links of everything being listed?

Mr DUNCOMBE - We tend to use a few.

Mr BEST - Do you have those links on yours?

Mr DUNCOMBE - No, I don't think we do.

Mr BEST - If there was, say, a Tasmanian disability web site that had everything as best as could be provided, do you think that might help?

Mr DUNCOMBE - Yes, that would be good. What we use a lot is the Independent Living Centre. There are lots of links from their web site. All their web sites are linked, so we tend to start there. There is another one called IDEAS.com and we use that a bit.

Ms PUTT - I wanted to ask about hardship and how frequent it is that you find people need help but just simply don't have any money?

Mr DUNCOMBE - We find that a lot. We are probably in a better position to help those people than a lot of other services because our labour is voluntary. The volunteer is the best person to assess that person's financial position and they won't charge for their inputs. They say, 'The poor person hasn't got anything so I'm not going to charge mileage to go out there. I found this up the back of the shed and I'm going to donate it'. We get by that way. There is a lot of financial hardship.

Ms PUTT - I am trying to explore how much that is an impediment to people getting what they need. It is important to know whether it is coming through to you.

Mr DUNCOMBE - Yes. I would say we find that a lot.

Mr WHITELEY - I think, from the committee's perspective, we should ask you to take our appreciation back to your volunteers. We don't have too many groups come in here not looking for money. I think the work you do is just fantastic.

DEPUTY CHAIR - I think you could be assured that various members around the table, when they do their next electorate newsletters, will be featuring TADTAS. Thank you very much for your time. It has been very much appreciated.

THE WITNESS WITHDREW.

Ms MEGAN MORSE, ALLIED HEALTH MANAGER, CALVARY HEALTH CENTRE AND **Ms CHRISTY DONWARD**, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

DEPUTY CHAIR - If you would like to speak to the committee around your submission and any other matters you would like to bring to the table today, members will then jump into questions but hopefully in an orderly fashion.

Ms MORSE - Okay. I manage Allied Health for Calvary Health Care Tasmania and I guess the context in which we have come along this afternoon is in relation to the services that we deliver under contract for the Department of Health and Human Services in the south of the State. We hold a contract and have done for quite some time that provides children's therapy services, hydrotherapy and communication access to people living in the southern half of Tasmania; the 62 telephone area code is our geographic catchment.

Our children's therapy service provides services to about 1 000 children and families at any one time, up to 650 to 700 new families in a year, so we have a very steady flow of families in and out of our service. As we have talked about in our submission, our communication access service is a smaller program that provides support to both adults and children. I guess the relevance for us in terms of this particular inquiry is that our agency is a primary prescriber and issuer of equipment. We do not fund equipment but we spend an awful lot of time securing funding for equipment, applying for funding for equipment, and so on and so forth. So there is a significant interface for us in terms of both our children's therapy service and our communication access service with the southern Community Equipment Scheme and that is the context in which we very much jumped at the chance to share some feedback with you about our experience of working in the system as it is currently structured.

Mr WHITELEY - So you are provided with an amount of money each year?

Ms MORSE - That's right.

Mr WHITELEY - And then you manage that according to your own guidelines?

Ms MORSE - Yes. We are provided with a target number of hours of service that we provide to a targeted range of adults and children, and we have gone through the kinds of services that we provide. Certainly the group of children who are most likely to be clients of both our service and the Community Equipment Scheme are those who fall into target group 1 of our contract, so children who have a neuromuscular or musculo-skeletal disorder are the kids most likely to have significant equipment needs. That is not to say that there will not be other kids in other target groups, but they are certainly the dominant group of children with significant and ongoing equipment needs.

That covers the broad spectrum of equipment in their home environment, equipment in their child-care or school environment, equipment that is geared towards mobility, equipment that is geared towards manual handling, equipment that is geared towards independence at mealtimes, facilitating communication - that very broad spectrum of participating in the community as fully as possible in whatever community context is relevant and appropriate for that child, depending on their age.

That is also true of our adult clients in the communication access sense and, to give you a little bit of a sense of how that program works, its primary focus is communication but also on access and independence with environmental control and things like that. There are a lot of gadgets and gizmos in a communication access sense.

Mr WHITELEY - The base of your contact within the community is obviously very broad if you are talking about 750 or so clients a year. Do you have a comment to make in relation to the unmet need that lies somewhat dormant in the community? What do you imagine to be out there as far as unmet need is concerned?

DEPUTY CHAIR - Just so can I clarify, are you asking for a clarification on the equipment that you currently cannot provide to the clients you have, or are you asking them to guess how many clients could be out there?

Mr WHITELEY - No, I would imagine that you would come into contact with people that maybe you cannot help. I suppose I am just trying to get a fix - as I have asked many of the people who have given evidence - as to what is out there. Do you imagine that people have pretty well just given up? I note in your first response to our terms of reference that you talk about the fund being thoroughly under-resourced, and that is fine - I do not think that is any surprise to any of us; every witness has given that evidence - but I think you know what I am trying to say. What is out there?

Ms MORSE - Just in terms of our program, with our children's therapy service, I am reasonably confident that as an agency we've got pretty good exposure to that population.

Mr WHITELEY - So there's not a lot of people lying dormant in that area.

Ms MORSE - No, I don't have the sense of that. The children's therapy service has a very open process where referrals can be generated by the families themselves. The two biggest referral groups for the service are the child and health parenting service and the Department of Education.

Mr WHITELEY - Maybe they are at the stage of life where they are at the most point of need and they go looking -

Ms MORSE - Yes. It's about being tapped into other services, so I guess in terms of exposure to that population I am reasonably confident that our agency has good coverage of that population. In terms of their unmet equipment needs, I think that's probably where it starts to become a much more relevant question. I guess the issue for us is that it's not a situation where you set that child up and then walk away and say, 'You'll be right', because kids grow and develop. Some of our children are making progress in a positive direction and some have conditions which inevitably are going to lead to their skills and abilities deteriorating. So the children's needs continue to change over a period of time; they are not a population where you can set them up and realistically expect, as you might with an adult client, that they will be right for x number of years.

Mr WHITELEY - Just on that, within your charter of the arrangements with the department for your money, do you map the perceived need, like a life plan? Do you do that when you start?

Ms MORSE - Yes. It would probably be a little bit ambitious to describe what we're doing at the moment as life planning, but we are certainly engaged in quite proactive planning with our families, although in the sense of being able to plan for equipment needs we are constrained in that because we don't have the funding. All we can do is put forward recommendations to another agency which then makes decisions around what their resource base and their capacity is like. The more people who are involved in that process, the less any one agency is able to be providing that family with particularly definitive answers around what might be available and when it might be available.

Certainly from an agency perspective we are very much focused on trying to deliver services to families and the way we work in very close partnership with families. We are wanting to reflect their ambitions and priorities for their child, with very much a forward orientation that we know that child is going to have significant milestones around moving into school, moving from primary school to high school, moving from high school to future study, employment, and other living contexts. There are obviously some very key milestones along the way that will often be the trigger for a revision of their equipment needs and requirements.

The nutshell answer to your question is that I think there's a lot of equipment that isn't being provided in a sufficiently timely fashion at the moment to maximise the benefits that a child and family would derive from having access to it.

Mr WHITELEY - I suppose we all know that children grow very quickly, so if you've got to wait for two years, the kids are a fair bit different, aren't they, from when they're three to when they're five?

Ms MORSE - Yes. There's a very strong body of evidence that shows that the faster we provide exposure particularly to issues around the use of communication devices, and the faster that child has access to that equipment, the more likely they are to use it successfully. Delays have really been very significant in terms of the long-term outcomes of that intervention, and we are talking about some fairly serious dollars there, so if down the track we're not getting maximum benefit from spending that money because we were a bit slow at the start, it's a really unfortunate outcome.

Ms PUTT - I was interested in your submission where you talk about the inequity that results from having to make a co-contribution. Could you perhaps outline that? In my understanding, it's sort of pot luck: if you come along with a need and there isn't a bit of equipment, then you've got to contribute a major proportion of the money up-front, yet the equipment, when you no longer need it, reverts to the pool and someone else could come along and if it's in the pool, not have to make that contribution. But if you are going on to a new bit of equipment that's not available you've got to make the contribution again - am I right?

Ms MORSE - I think I must have made my point clearly because that is exactly right. Again, that obviously impacts on our paediatric clients and families again and again potentially, because if you are the first family that has that child with that need you are going to keep being the first family, in all likelihood.

Ms PUTT - So each time you are going to have to suffer the impost.

Ms MORSE - That is right. And to pick up on the question that you asked earlier around repairs and maintenance, again, that impacts on these families again. If they have chosen another path and funded it more independently they are going to bear all the repairs and maintenance costs as opposed to being, to some degree, subsidised and supported with maintenance if they stuck within this existing system, but they do not have a piece of equipment at the end that they might be able to stick on eBay because they have to hand it back. That is a really big impost on our cohort of families.

Ms PUTT - And considerably unfairness in terms of the application of that.

Ms MORSE - At the moment it would be difficult to suggest that it is not unfair.

DEPUTY CHAIR - If I can just follow on from that, we heard earlier the suggestion about the need for a grievance or disputes process from evidence that was given by a previous witness. Would you agree with the idea that through the equipment scheme there should be some sort of disputes committee set up with a person with a disability on that committee so that hearings can be held around issues of unfairness that might arise? I do not know how many cases you see where people say that they would like to take this somewhere because it is unfair and there is no avenue for that?

Ms MORSE - The fundamental ethos of consumer participation is always a good thing philosophically from our perspective, so I am wanting to give good credit to that. In our experience of grievances, it is not a really strong feedback that we receive. We certainly receive feedback that it is not a closed communication loop; that families whose applications have been approved and told that funding will be forthcoming are wondering when more funding will be forthcoming, so the fact that the time lines are very nebulous at the moment is a source of frustration perhaps for therapists as much as families because they are in that limbo of whether to pursue other options but you cannot pursue any other options until the CES categorically says, 'No, the money will not be forthcoming'. The family are stuck in a holding pattern until something happens. I would be putting my hand up for a more closed communication loop probably as a precursor step to the need for a formal sort of complaint or grievance committee-type thing.

From a clinician's perspective, I am sure you have been briefed that the schemes have a multi-agency review panel and I think the sense in the therapy community at least is that that is a pretty effective process that is done in a way that sits pretty comfortably with us, short of the fact that it is loaves and fishes and there is not just the money to go around.

Mr WHITELEY - Given what they have to deal with they do a pretty good job.

Ms MORSE - Yes. But the sense of that ability to say it is either coming or not coming and if it is coming it is coming in this sort of time frame, that would take a lot of the frustration around just being stuck on a waiting list out of the equation.

DEPUTY CHAIR - Thank you.

Mr WHITELEY - Is there a similar service or charter or expectation provided in other parts of the State, and who does it?

Ms MORSE - From the perspective of?

Mr WHITELEY - Well, you deliver this service provision in the 62 area code - who does it in 63 and 64?

Ms MORSE - There are like agencies in the north and the north-west. The children's therapy service that we provide at St Giles is the like provider in Launceston.

Mr WHITELEY - So that is the similar in your case.

Ms MORSE - That is right, and the Child Development Unit is the like agency in the north-west. From the perspective of communication access, the Independent Living Centre in Launceston is the like provider up there.

Mr WHITELEY - Regarding the issue of the supply or the inadequate number of physios and OTs, do you have any comment to make? Can you give us any pearls of wisdom. I should not presume what the report will say but I can't see any way that the report won't include something to do with the lack of numbers. It has been put to us that we don't even train them here anymore. If we had the magic wand, what do we need to do?

Ms MORSE - If I had the magic wand, to put it in a nutshell for you, in my experience of allied health professionals, it is not a problem that is unique to Tasmania. There are some parameters down here that are different to some of the mainland States. Certainly the fact that we don't train professionals here is some degree of disadvantage. The way an agency such as ours manages that is that we are very proactive in accepting student placements. We bring people down in the course of their training, show them the opportunities and showcase the excellent things our agency is doing and hope they will come back. There are mechanisms by which you can manage that, the sense of where tertiary training is going to be provided and who provides it.

Mr WHITELEY - I suppose that is only one part. We have heard a bit of evidence about whether or not it is an exciting business to be in. Pay is obviously one issue. Can we do more to promote the vocations alongside the need here, do you think?

Ms MORSE - Again, our experience around that is that we are very proactive in accepting work-experience students. There is the capacity to bring a young person into our agency and show them the diversity of options within allied health. I guess the concern is that people generally can identify physiotherapy and occupational therapy. The discipline that I have the most difficulty recruiting and retaining is speech pathology. You could pretty much lay your options out here and I would do a deal with you in terms of speech pathologists at the moment. It is a chronic, ongoing, unremitting shortage that gets to the point where it then starts to put pressure on our remaining members of staff. The critical mass in speech pathology is the biggest discipline challenge that I have as a manager over the four years that I have worked in Tasmania. I guess the crossover here in terms of communication is that that is the discipline that has the greatest interest in the kinds of augmentative and assistive communication devices.

Mr WHITELEY - What's the shortfall in numbers?

Ms MORSE - At the moment I have half the speech pathologists I'm supposed to have.

Mr WHITELEY - What is the number that we could do with in Tasmania tomorrow?

Ms MORSE - I would take three.

Mr WHITELEY - I'm just trying to get a handle on how big the problem is.

Ms MORSE - It gets to the point where agencies start to pinch speech pathologists off each other.

Ms DONWARD - There are two issues there. There is the recruitment and retention, which you were talking about, and the number of therapists per capita compared to the other States. We are about half of their national average. It's not just a matter of retention, it's looking at the other issue as well.

Mrs BUTLER - How do you measure success? We have had earlier evidence today saying that there were virtually no benchmarks established and it is difficult to measure success. What sort of methodology do you use?

Ms MORSE - I guess in some respects that is a particularly difficult question for us to answer because of the scope of clients that I am responding in relation to. The way we indicate success in a very small child would obviously be different to our adult clients. We are using a range of objective measures within our agency. We have a range of very key parameters around safety in particular of our children our primary clients, and occupational health and safety when we are thinking around child-care workers and teachers. There is a range of mechanisms by which we would measure success. In our adult clients the abandonment of devices is a really genuine problem. It just gets too hard and people shove them in a cupboard. I guess the continuing use of a device is the first sign that you are still in the game. I realise that is a fairly vague answer, but short of being able to speak around specific instances again it is an issue that, because of the scope of clients that we work with that, it is among things that we will be using. But the short answer to it would be that all of our clients have functional clinically orientated goals and so each of them would have a measure of success.

Mrs BUTLER - Is that determined in consultation with the client?

Ms MORSE - With the client and family or the client and carers, in the instance of an adult client.

Mrs BUTLER - So would you see independence as one of the main aims?

Ms MORSE - Yes, and participation within the community context of society.

Mrs BUTLER - Do you use a casework approach?

Ms MORSE - Ah -

Mrs BUTLER - Do you have a caseworker?

Ms MORSE - That does not tend to be a model that our agency operates with. I guess from the perspective that our emphasis is on the provision of service, brokering services is not really the business that we are in. It is much around the provision of services.

Ms PUTT - I presume that a part of that is having the capacity to forward plan equipment that might be needed in the future and being able to provide it at the time it is needed. Would that be right?

Ms MORSE - Absolutely. The approach we would take to that is to be as proactive as possible in our negotiations and discussions with the family with their other care environments, in the instance of our clients who are also Department of Education students or our adult clients who may be living in a supported residential environment, that we can see that there are things out there that we need to be prepared for. We certainly know that the system lacks the capacity to respond to us rapidly and so the quicker we can get something on paper the better. But again, I guess it was interesting for us. We obviously were able to be here, so we heard the feedback from the lady who had started before we arrived. But having had a briefing from a consumer and to hear her talk about not being keen on having a hoist yet -

Mr WHITELEY - Robyn?

Ms MORSE - Yes. I guess the challenge for us from an agency perspective would be that when Robyn has decided she needs a hoist we are not going to be able to provide it on the spot. The system cannot do that. So I guess that is where the tension exists between what either individual clients or what families are ready to accept that might not -

Mr WHITELEY - I suppose there is probably a difference between three months and three years though?

Ms MORSE - Absolutely. But it is not a responsive system at the moment.

Mr WHITELEY - You were never going to get it tomorrow, even in the best system in the world.

Ms MORSE - No.

Ms PUTT - Success will be at a point in time but will stall under the current system.

Ms MORSE - Yes. I guess the issue at the moment is that when it has been decided that a piece of equipment is required, it is way out here. We could have done the best forward planning in the world but if a family is not ready it may be that we are just not able to move forward until they are ready. The system cannot to respond to that, unfortunately. So I take your point. There is no perfect answer to that.

Mr WHITELEY - If you want to buy a new car and you have the options you want on it it will take you two or three months, so it is no different.

Ms MORSE - No, but that puts people at risk.

Mr WHITELEY - Oh sure.

Ms MORSE - So you might get -

Mr WHITELEY - If it has to come from Germany or somewhere it is not going to come tomorrow is it?

Ms MORSE - That is right. So there are some real genuine practical challenges around that.

Mr BEST - Do you get any funding for voice output communication devices?

Ms MORSE - Yes. Again, as an agency we do not hold any funding for equipment.

Mr BEST - No, do you receive funding?

Ms MORSE - Theoretically. I would expect that we have applications along that line approved. As to whether or not that funding has been applied, that would be a different answer. So again, we talked in our submission about the fact that at the moment the Community Equipment Scheme rates communication devices as a priority 4. There are times at which the Community Equipment Scheme gets down to priority 4 in terms -

Mr WHITELEY - We cannot even get the waiting list on that.

Ms MORSE - So, in theory, it is something that is being funded but not purchased.

Mr BEST - So you are not receiving funds in relation to voice output communication devices. Those have to be privately fundraised, is that right?

Ms MORSE - That would be another option.

Mr BEST - That is the only option isn't it? Are you buying them?

Ms MORSE - No.

Mr BEST - Finally, do you see a need then? Do you think that category 4 is fair enough?

Ms MORSE - No, we would see it as a very fundamental human right to be able to communicate. Again, we have talked about the need for some reconsideration of how priority is attributed with communication devices and the really significant technological changes in that area. No, I cannot sit here and say that I am at all comfortable with that.

Mr BEST - Thank you.

DEPUTY CHAIR - Any other questions, members?

Mr WHITELEY - Plenty. We can follow up if we have any, if you do not mind? We have your e-mail.

Ms MORSE - Yes, absolutely. We are very pleased to have had the opportunity to put something on paper and come and speak to it today.

DEPUTY CHAIR - Thank you very much for taking the time to come. We greatly appreciate it and I am sure you will look forward to our report.

THE WITNESSES WITHDREW.

Ms ROBYN JEAN SHEPPARD, AUSTRALIAN PHYSIOTHERAPY ASSOCIATION, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Finch) - Thank you very much for the submission. Did you prepare this?

Ms SHEPPARD - I put information into it, as did a number of other members of the Physiotherapy Association from all three regions.

CHAIR - Okay. It is very fulsome and we appreciate the time that has been taken to present that to us. It is very helpful indeed. It has been one of the topics of discussion in our deliberations.

Ms SHEPPARD - I also wear a double hat in that in the south I represent the paediatric group, along with an OT, on the committee for allocation of funds. I have been doing that for the last 12 years so I have a bit of background knowledge. Over the 12 years I have been doing that, the funding for that service, from when it was based out at St John's Park and then moved into Davey Street, has had minimal increase but the cost of equipment has gone up exponentially.

Also there has been a vast increase in the age of people who are being kept at home. There has also been documented surveys of the general demand for bariatric equipment for obesity has increased over the 12 years. Also the range of equipment has increased, so where there were standard shower chairs that you sat a person in to shower, now because of people's deformities, they have more customised ones. Sometimes those are important. Sometimes the standard is fine but sometimes you do need something that is specialised to manage that person at home.

Just in looking at the strategies and policies and practises, I wanted to highlight that down here in Tasmania we have a number of suppliers but they have a limited range of equipment to trial. That is often quite difficult when you are looking at customised equipment. That has led to, I would say, probably about 20 per cent of wheelchairs or commode chairs or some other sort of aid being inappropriately prescribed. With the therapies down here we get a lot of new grads through - we have a lot of old ones - but because of the lack of training facilities here our experience is from where our practical experiences come through. We do not have supports of schools and you get a big throughput here, so retention of allied health staff actually is also a barrier within this - being able to clearly say this is what should work and this not. Lack of that ability for those inexperienced therapists to trial equipment comes into that.

Mr WHITELEY - Is the inference that we may be missing out on being at the cutting edge because of the lack of people staying and bringing their contemporary knowledge into this State? Is that unfair?

Ms SHEPPARD - It is quite difficult to retain younger staff. They come down here and then they go off on their trip - and the lack of having a training facility here. I know UDRH does a lot

Ms SHEPPARD - the lack of having a training facility here. I know UDRH does a lot and there are discussions within the Health and Tas uni looking at doing some sort of clinical training school for physio. However, it is difficult for allied health staff to get that support. We cannot expect the suppliers down here to have a huge range and then it is difficult getting it across here to trial it.

Mr WHITELEY - I saw that in your first point. It must be an arduous task to get it, trial it and send it back and get another one.

Ms SHEPPARD - It is and not always can the Community Equipment Scheme pick up the cost because the suppliers are now not picking up the cost to bring equipment down for you to trial. You have to pay for at least one way for that to happen.

The Community Equipment Scheme, as I know from the south and I presume the north have the same, administrative staff have been working there for a while so they pick up knowledge but they do not have a good knowledge. Wendy and Jo down here have good knowledge of equipment and what there is, but as soon as someone backfills they have no idea and you are better off going down yourself. That is a big area. If one of them goes off on leave it takes so long to get a replacement and sometimes they do not have replacements.

The staffing level has also affected the maintenance, cleaning and re-use of equipment and that is one of our biggest issues. I and Peter and a lot of the other therapists will try to re-use existing equipment prior to purchasing new equipment, so we are quite cost-effective in that way. At the moment I have two \$7 000 strollers to try for one child, trying to make up one because they have been cleaned and pulled apart and then they are just put in a room. So the staffing to clean and put the pieces back together again so that it is a complete unit is not there. That is one of our biggest things. I took a stroller out for someone to use. It has a seat that is an integral part for the harness and the seat is missing. The stroller is there and it is fine. It has the top parts of the harness but the seat is missing.

I nearly did bring you a picture, if any of you have ever been in Davey Street, of trying to get into some of the store rooms where the equipment is kept. It is an occupational health and safety issue for all those staff working in there. My manager has said that we are not to go up, nor are any of our staff to go up, because you have to remove all these big, heavy motorised wheelchairs and scooters, to get to some of equipment in the back store. Standard equipment is quite easy to get to but the customised equipment is not. So their storage facilities were quite crowded at St Johns Park. Then it went to the nice area and then it was moved across to what used to be the kitchen, so it is very crowded there for them. So they try very hard but it is a never-ending battle. There are lots of pieces of equipment there in parts. They have told us now just to order a new one because they do not have the time to put parts together to make a whole.

Mrs BUTLER - At \$7 000, a new one?

Ms SHEPPARD - Yes, standing frames are \$2 000 and there are two of them up there but we have had to order three new ones this time. We have tried to put them in with the Equipment and Technology Library Service, which services equipment for children in

schools. They have a very good management system of cleaning, maintenance and return, and that is not happening.

CHAIR - Where is that storage area?

Ms SHEPPARD - In Davey Street.

CHAIR - Is it purpose built storage area?

Ms SHEPPARD - No, they were put into what used to be the kitchen up at Davey Street. So they have a couple of pokey offices and then they have equipment all over the place.

Mr BEST - Whose building is it?

Ms SHEPPARD - It used to be the kitchen of repatriation. It belongs to the Health department. When they moved the Adult Rehabilitation Service to there, that took over the part of the building that the Community Equipment Scheme was in. The community equipment scheme did a shuffle and was moved out further.

Our Tassie therapists for adults said that having the satellite store at the Royal has been quite good because that has meant that they have some standard equipment for discharge. They can't discharge clients without appropriate equipment. Discharging a high-needs client can take up to \$30 000 by the time you put a bed and everything else in. That is probably one-quarter of the annual budget for the Community Equipment Scheme. Some 12 years ago this scheme was purchasing equipment to enable people to get to doctors' appointments, so it had a bit of a community feel; it was keeping them in the community. Now basically it is a scheme to keep people out of hospital. Unless you are a priority 1 rating, which means you are at risk of not being able to live at home, if you have obvious pressure sores or pain or no equipment, then that is the only way you get priority 1. Otherwise you are a priority 2, and a priority 2 may stay on that waiting list for 18 months to 2 years or longer than that.

Mr WHITELEY - We had evidence given to us this morning from Margaret Reynolds, who suggested they should be two separate funds, with community living and the medical side separated and funded adequately for both.

Ms SHEPPARD - Other States have had a hospital-based discharge fund that I have worked in.

Mrs BUTLER - Would you recommend that?

Ms SHEPPARD - The funding in other States is capped, too. In Victoria, children have to apply for funds to get a pair of orthotics; here we are lucky that they can get orthotics from the service in Davey Street. There are pros and cons on both sides. Having a community and a hospital-based funding probably has merit.

Mr WHITELEY - A discharge-type program?

Ms SHEPPARD - Yes.

The other thing with cost of equipment is the amount that families are having to fundraise. It is fine when you have children because they're young and cute. It is a lot easier to fundraise for children but if you're trying to get a motorised wheelchair for an adult then that could be something like \$20 000 and the Government puts in \$6 000. Where do you get the rest? We used to go through Disability Services and they were great, but they don't have any money. So it is now getting back to going through all the charitable trusts. Some people just don't want to do that and you have to respect their wishes. It can mean that trying to get a piece of equipment for someone can take two to three years.

Mr WHITELEY - The Government puts in \$6 000, which is the cap; that's if they have it.

Ms SHEPPARD - Yes.

Mr WHITELEY - That's if there's money in the tin. Not everybody who requires a wheelchair gets the first \$6 000.

Ms SHEPPARD - No. Some of our physios said it was difficult knowing whether they fitted into the loan or the hire status. I don't have a problem because I treat children and all the children I treat have a disability child allowance. However, when you get to adults and if they don't have a health care card, can they still borrow it at \$20 a month or are they ineligible to access that because they don't have a health care card. Then they have to purchase the equipment themselves.

Ms PUTT - The rules are unclear?

Ms SHEPPARD - I did not have a problem with it; I am just noting this. With the hardship funding, we know the clause is there but it is quite a long and involved process. I haven't had any families that have gone through it, but I think the north-west has.

The eligibility of having to live in the State for three months is quite difficult if you have a child with a disability that is transferring across to here. With some community equipment schemes, if the parents and the therapists are forward-thinking, they will get that equipment handed over to the equipment scheme down here, but that does not always happen. You find that people come here with no aids and very little equipment and they have a big child who they have to lift manually and it is a huge risk to them. Things like hoists and change-tables are difficult.

I know in the south people have been a lot more aware of communication aids and allocating that \$2 000 when it comes to the basic need of being able to communicate. That has happened a little bit more in the south, but from this I see in the north-west that unless it comes down to, 'I want your attention!', they are not being funded with the minimum of \$2 000. That is an area where technology has really improved; where people previously were answering with a 'yes' or 'no', they now have the ability to use some technology to indicate their basic needs and that has not been taken up. Mind you, \$2 000 does not go far with \$15 000-\$20 000 machines. I note from the adult point of view here that they were saying that getting some of their items is very much dependent on whether or not they get their EACH package, which is their Extended Aged Care in the Home package. It is a new package that has come out to support people. Until they

get that package they cannot say yes because sometimes those sort of aids come through the package and sometimes not.

There is that unmet need for home modifications and assistance with transport, van purchase. I do not know what the solution is. I know that in England they have their allowance put into home modifications and then they pay back the Government over a period of years, so that their pension or whatever goes in, the van is purchased and then they pay the money back over the years. That has been one way, but I know that nationwide the purchasing of vans for transporting someone in a wheelchair is very difficult. It is the same with home modifications. Other States do have some part of home modifications in their guidelines but we do not. Peter will probably speak more on home modifications.

There were also discrepancies. I know that they tried to even things up a number of years ago when it all came under that same umbrella, but there are still discrepancies between the regions of the north-west, which are quite limited, and the south, which has more equipment. One of the things that we put in was perhaps whether there is some way of having a centralised database so that you are not just having the equipment here but it is centralised and it can come down.

Mr WHITELEY - I noticed in your submission that you said it would even be helpful to have photos attached so that you can call it up and say, 'Yes, that looks like it might be something we are after'.

Ms SHEPPARD - Yes, we have done that with our equipment that we store in a garage. It is pretty old; it is Douglas Parker equipment that I won't let them throw out. It may have a use one day. If you have a digital shot of it, which is so easy to do now, then you can easily have that and there is that picture -

Ms PUTT - You should be able to take a photograph and make an electronic file in five minutes.

Mr WHITELEY - Just do a hyperlink straight to a gallery - it's no big deal.

Ms SHEPPARD - The SNSS funding people have now started that; they have a bank of equipment.

Mrs BUTLER - What is SNSS?

Ms SHEPPARD - It is the Special Needs Support Service for Tasmania. It is Commonwealth government funded and they provide equipment for children with special needs in creches and day care. They have started up an electronic database so that you can see what they have got.

Mr WHITELEY - But there is not a centralised database of any form at the moment, is there?

Ms SHEPPARD - No. I have a tilt table on loan from the north-west and I've been told that that's a permanent loan now. That was all done by Wendy ringing up and seeing if there

was one around for trial, so we had it for trial and now we've got the parts for it to make it work effectively. That would make reusing of equipment a lot easier.

Mr WHITELEY - How much of you and your colleagues' time would be spent, shall we say, trying to put a jigsaw puzzle together that's got a lot of bits missing, in the sense of you know you've got a need, you've got a client. We would all be the same, I'm sure, the human need would say, 'We're going to fix this, I don't care what it takes. Whether I've got to talk to a Rotary Club, whether I've got to beg, borrow or steal, we'll try and fix this.' How much of your time would be spent doing that compared to what it could be like if there was an adequate system providing the stuff?

Ms SHEPPARD - By the time you are writing, trialling and doing things, we have put down that for every hour face-to-face we spend with a child, we end up spending about six hours chasing up equipment and other things. With the severe children who need equipment, the ones who can perhaps drive in a wheelchair, and the ones who cannot drive and have to be pushed around, I bank on about six hours of following up equipment and other things for them, and every time I see them it just snowballs.

Mr WHITELEY - So a lot of time.

Ms SHEPPARD - Yes, a lot of time, by the time you write submissions and you try to get equipment to trial -

Mr WHITELEY - Six hours for every one hour face-to-face.

Ms PUTT - Some of that time you would inevitably spend, whether or not there was an availability, wouldn't you?

Ms SHEPPARD - Yes, but -

Mr WHITELEY - But not six hours.

Ms PUTT - Not all of it, no.

Mr WHITELEY - You'd think it would be fair to assume you'd write a brief submission to give authenticity to the claim. If they can't trust their physios, who can they trust? But six hours, beg, borrow or even stealing is -

Ms SHEPPARD - For one piece of equipment, I couldn't write to the Community Equipment Scheme because it was ineligible, so I wrote to Disability Services. But then I wrote to the Lions Club and the Rotary Club in both those areas, and I've heard back from no-one because she didn't fit the guidelines for spinal and she didn't fit the guidelines for the CP Association, and you have to check up on all those things.

Mr WHITELEY - My point was that there is time lost in doing what I suppose what you are trained to do.

Ms SHEPPARD - Yes. I was just checking that I had mentioned most of the things.

Mr BEST - I am particularly interested, and in fact I want to have a look at the storage at Davey Street. Where are things stored, for example, in the north-west or the northern end of the State? Do you have any idea at all?

Ms SHEPPARD - No. Probably in the north-west it would be somewhere at the North West Regional Hospital.

Mr BEST - Maybe Park Street, or something.

Mr WHITELEY - Parkside.

Mr BEST - Parkside - sorry. The final point that you finished on was that you were looking to try to access equipment for a specific need for a child. We had some other discussions earlier on today about some sort of better network situation as far as innovation of solving things with equipment and new ideas and things.

Ms SHEPPARD - Utilising the equipment technology library?

Mr BEST - Yes. Do you think there could be some sort of better managed system where it's easier to source or quicker or more efficient? I think Mr Whiteley was talking about waste of time and things like that.

Ms SHEPPARD - We often utilise the equipment technology library in the paediatric area, but there's not something like that for adults. The equipment technology library is funded specifically through the Commonwealth for children in Education department facilities, and they have stacks of equipment up there.

Mr WHITELEY - That's for skills funding?

Ms SHEPPARD - No, that's separate; that's a different one. This will be kindergarten through to the end of school. Once you go on to TAFE or uni we then have to try to find equipment in that facility but the equipment and technology library, which is based in the old Wingfield, has a lot of equipment and it is very nicely stored, tracked and maintained in a great condition. Mind you, they have a mountain of paperwork we have to fill in to get a piece of equipment and track it through, but they do track and they now have electronic printouts of what equipment children have and in what schools.

Mr BEST - Where is that, sorry?

Ms SHEPPARD - It's based at Wingfield in St John's Park and Ingrid Howe is managing it at the moment because Virginia McCann -

Mr BEST - And that is Federally-funded and State-run?

Ms SHEPPARD - Initially it was Commonwealth and I think they still get funding through grants and things to upgrade their equipment.

Mr BEST - Might it be State-run, though?

Ms SHEPPARD - It is run within the State and it services the whole State.

Mr BEST - Is it State department managed or -

Ms SHEPPARD - No, it is under the auspices of Cerebral Palsy Tasmania

Mr BEST - Okay.

Ms PUTT - I see in your submission - and I do apologise for coming in a little late so I do not know if you have spoken to this -

Ms SHEPPARD - About the position statement at the end?

Ms PUTT - No, it is actually in the submission itself - an observation that in other States there is a third funding source that is not really very big here, which is local businesses. I was interested in that. It is on page 4. Charitable organisations we have heard about and the Government, but in WA, for example, local motor companies providing bands and so on. Do you know any more about that?

Ms SHEPPARD - No, but I could get Sue to forward the information through.

Ms PUTT - Thank you, that would be useful.

Ms SHEPPARD - I know WA have their big Tatts lotto money which goes in but it basically goes in for paediatric stuff.

CHAIR - You were talking about more and more these days we are keeping people at home and subsequently there is an increase in need for equipment. Is there any link between that circumstance and this problem of obesity where people are becoming more obese so there is a greater need for equipment as well?

Ms SHEPPARD - I think that is coming through with the adult population and where you have obesity, diabetes and joint problems like arthritis, there are a lot of requests for aids and equipment for those people. Obesity really compounds diabetes and it also compounds any stress and strain on joints so that what limited mobility they have is hampered even more, but I do not have any statistics on that.

CHAIR - So if obesity and diabetes are increasing problems and people are living longer, we need to get our act together now for the problems further down the track.

Ms SHEPPARD - I know down south they are looking at the windfall they have of actually purchasing standard bariatric equipment, so they are starting to cater for that rather than having to go through the customised version.

CHAIR - Did you call it bariatric equipment?

Ms SHEPPARD - Bariatric means standards approved for greater weight. There is a greater range of bariatric equipment now; 12 years ago it was something special whereas now - and especially with litigation and things - people are looking a lot more at the weight limits of hoists, shower chairs and crutches. The other day we had a lad who was 140

kilos on crutches that are not designed for that weight, so we had to get new crutches, which were \$200 or something, that would carry his weight.

CHAIR - Any other questions, members?

Mr WHITELEY - The submission is pretty consistent with everybody else's.

Mr BEST - There are some very interesting points you make.

Ms SHEPPARD - I suppose I come from very much a practical rather than a managerial background.

Mr WHITELEY - We have had a lack of physios, OTs and speech pathologists we heard just before lunch. Do you have any solution in relation to how we can encourage more people into the field? Have you, as an organisation, a view or strategy for that?

Ms SHEPPARD - No. Retention is difficult. The lack of a clinical school down here does mean that there is only a certain amount of advancement and a lack of a career path. If you want to work in paediatrics in the south, you work here or in the north and north-west. With adults there is a bit more freedom to move around between services, but within paediatrics it is specialised. It is not compulsory now in the training schools. There are only a few schools that have paediatrics as compulsory, so it is a post-grad thing.

CHAIR - With recruiting, do you find that the mainland States are able to attract the staff away by offering them more money? Are they in a competitive situation?

Ms SHEPPARD - It is often more the career path. It is that ability to go up in level and recognition for your standing as a practitioner.

CHAIR - And the financial reward comes with that?

Ms SHEPPARD - We've had a few who have rejected a position because they have been earning more in outback Alice Springs than they could have got down here. In the new pay structure you go from 1 to 2, but then there's no competency-based level where you can go up in the clinical field from 2 to 3. It is still the old system where you couldn't move from a 1 to a 2 unless you had a position to go to. From a paediatrics point of view, it is equally as hard getting paediatric therapists in the Melbourne metropolitan area and outback Queensland as it is down here.

CHAIR - Thank you very much for your time, Robyn. We appreciate it very much.

THE WITNESS WITHDREW.

Ms PETA RAISON, OT AUSTRALIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Peta, thank you very much for joining us. You have seen the process and how we work. Would you care to speak to your submission and tell us what you think we need to know?

Ms RAISON - I think there's been a lot said that is very much the same. I think you will probably find from our submission that it is very much the same as Robyn has said. We think that with the CES there certainly is a limited human and financial service. There has been such a rise in the cost of equipment and I think that has been one of the biggest things. I think as well that it has gone from just being an equipment place to sustaining people at home. One of the big things for us, with anybody, to sustain them and keep them in the home has been the focus that we all work from now. That has grown harder and harder to do when you need the equipment to do it.

In my other role I work as an occupational therapist at the Royal Hobart Hospital. My predominant role is paediatrics. It is a bit different than Robyn's role in the fact that Robyn's children are very specialised. You need customised chairs and things. It is very difficult for children who have come in and are sick - oncology children, children who have been born with deficits and problems - and they are not necessarily going to receive funding for all things. A child who breaks a leg and ends up in a wheelchair may have problems healing et cetera, and to get them a normal paediatric children's chair and put a leg board on it so their little leg can stay up and be immobilised is nigh on impossible. I have a few old chairs that I have been fortunate to keep around; I tie them with string and I have wooden boards that my husband cuts and constructs for us at home. I could tell you some wonderful stories about the children at the hospital.

Mr WHITELEY - Where's the problem? You just need more husbands.

Laughter.

Ms RAISON - I do. One day our surgeons were being particularly demanding. They are working on it. For me it is very different. The palliative perspective is enormous for me and it is the same for our palliative adults. At my age now I do not have a HealthCare card and I do not have a pension. If I am now, God forbid, struck down with something that I need to have a hospital bed for because my family want to take me home to nurse me and look after me at home so I can die at home, and if SCES do not have any available, palliative have a limited number but you must die within a short time. So you have to be sure that you are going to be gone in a few weeks because there is going to be another bum in that bed. So they need it. So it is not possible for SCES to secure a hospital bed for me to manage at home. We hire them from Red Cross and they cost \$50 a week and you must have them for three weeks. So, come what may, it costs you \$150 to hire it. They are very good. They will deliver and collect and they are really good at doing that. But that is a real issue.

Mr BEST - Sorry, what sort of bed was that?

Ms RAISON - It is a hospital bed. If you are really trendy you might have one of those Japanese futons and they are very difficult to nurse from when you are on your knees down beside those. So any equipment to manage people at home makes life much easier. So as much as the push has been to get people home, manage them at home, how can we do that? Our houses are built two to three stories. They are huge. Showers over the bath. Steps to get inside. I could go on for hours. We do not have any money for modifications. We used to, under the old PADP scheme. We were able to access some moneys to do modifications. To do a bathroom now, just to remove a bath and put a shower in, will cost you nothing under \$10 000 to \$12 000. So it is incredibly costly and expensive.

Mr WHITELEY - It is probably a little bit outside our range. But it prompts the question, keeping someone in a hospital is at the highest end of the cost to the public purse.

Ms RAISON - Absolutely.

Mr WHITELEY - Equally, to be quite blunt, we may be facing someone being at the end of their life for six months, say. Nor is it probably good stewardship of public money, dare I say, to spend \$40 000 to do up a house. What is the solution? Do we need to move to something like a halfway house facility somewhere? What do we do then?

Ms RAISON - I think there are so many different ways. All of this can be broken down into so many different systems within our health system and I think we can all see that. It is so hard to answer all of those.

Mr WHITELEY - It is difficult isn't it?

Ms RAISON - I think palliative-wise my husband would want me to be at home and to look after me at home. As an occupational therapist I would do everything possible to do that. Many people manage with moving a bed to the lounge room which I just did this morning. I put the bed in the lounge. We put a commode by the bed. The family look after them. Palliative care nurses go in and see to them and they live like that for as long as they need to do it. They do not expect to have everything done up. The nurses can come and give them a wash. They have a wash in bed. They can manage those things.

It is certainly the longer-term ones in hospital with, for example, MS that are going to go home. We have so many more now with MS. We have so many people who are struck down later in life. We have car accidents even. Your MAIB does not necessarily cover you for all of these ongoing things to have at home to be able to do these things. Where you have had a massive stroke and you have ended up needing to go home and you cannot even get up 13 stairs and you are going to sell your house, what do you build? In Churchill Avenue, Rokeby and all of those places, all of us are building great big homes with all of that.

I think the Government is really doing well with housing needs and the units and the smart moves that they are making.

Mr WHITELEY - The ones they are building they are building well.

Ms RAISON - Absolutely. They are doing very well. You can put a stud along any wall. You have a walk-in shower with no lip. Sometimes people cannot even raise their leg, and most lips on a step are 90 to 110 millimetres. You go home and measure then on your shower. If you cannot lift your leg off the ground how are you going to get it over there to get in? There are all of those tiny little things. Go to a toilet and try to get up; 400 millimetre height and you cannot even get up from them. All of those things. We have to be much smarter when we are building things in our community buildings and in our homes. There is no reason toilets cannot be higher. There is no reason for all of those things. When people go home they have to get a raised toilet seat to go over the top of the toilet, as long as it will fit. You have to get a bath board to go over a bath because they do not have a walk-in shower. So their bum has to go on the board to have a shower, to have a wash. It is basic, basic stuff, basic things of how you have a wash and go to the toilet is what we need to have all this equipment and stuff for. And it is really, really hard. The equipment scheme try very hard to have as much standard equipment as possible. You can never get enough; you are always running out of shower stools or something. If it is going to be for six weeks or just short term I have no qualms; I will tell people to go to Chickenfeed and get themselves a suction mat and to go out and get the white barbie chair and bring it in and stick it in the shower and use it for six weeks. That is what we do. We let them know that it is not good that you can keep it there long term but it is going to keep you home and get you home in the short term.

Mr WHITELEY - In the short term it is okay.

Ms RAISON - It is, and there are many people who are not eligible to get anything else unless they go to hire them at Red Cross - if they have enough, but they even run out. There are no children's wheelchairs for hire for children from the hospital at all at Red Cross or anywhere. If SCES have got some for me they will do all they can to give them to me for me to be able to hire them. So therefore you have to send home a six or seven-year-old child in an 18 inch wheelchair to get through the house, to manage. They cannot self-propel because the wheels are too far back so they have no independence; they are stuck and perched up in this big chair.

Mr WHITELEY - All it is is a chair.

Ms RAISON - All it is is a chair, whereas if they can get a little kiddies' chair they can be off and get themselves around. They can get to school; it will fit through the doors -

Mr WHITELEY - What is one of those kiddies' chairs worth?

Ms RAISON - About \$900, \$1 700 if you need a lot of extras with leg bits on them.

Mr WHITELEY - But the average would be \$1 000.

Ms RAISON - Yes. But, mind you, there are some cheapies coming in. I picked up a Taiwanese one for about \$500 yesterday, which was really great - just for an average chair just to do a child.

Mr WHITELEY - Just enough to do someone for six weeks.

Ms RAISON - Absolutely. And I was donated a chair from Deb Carney's children through the oncology clinic, which was lovely, so we are able to utilise those. I try, as much as I can, not to have to draw onto the SCES. If your child is going to have its hips done even, you have still to find something. The child is in a hip spiker, it cannot move. Where are you going to put them? They will not fit into the pusher.

Mr WHITELEY - That is a problem right across the State?

Ms RAISON - Absolutely. The north-west are really hard done by; they really do struggle but they do a marvellous job up there.

Mr BEST - Why is that?

Ms RAISON - I think it is just because -

CHAIR - I wanted to jump in here just in case you missed the opportunity.

Mr WHITELEY - The Braddon boys - the minute she said north-west, we were in there.

Ms RAISON - I am a north-west girl. I think that the north-west do it hard. Often the children might have an operation done in Hobart because that is the State service. Then they have to go up to the north-west to go back. We try to get them as much as we can through the scheme. They do not have access to some of the things that I do. I am the only paediatric acute occupational therapist in this State that works full-time on an acute paediatric unit. We do not have any others. I think in Launceston they have the most beautiful paediatric unit which Hobart would die for.

Mr WHITELEY - It is. I saw it the other day.

Ms RAISON - But they do not have a full-time paediatric occupational therapist on that unit.

Mr WHITELEY - Recommendation number 10. Bodyguards and protection. We have to reinforce that unit up there and make sure this lady just watches them crossing the road.

Ms RAISON - Trying to fit 27 children this morning into 24 beds was a little difficult.

CHAIR - So the situation of children from the north-west requiring the operation in Hobart is that a regular thing though? The operations would not be done in the north-west, they would be done in the south?

Ms RAISON - Yes, they are done in Hobart.

Mr WHITELEY - Some of them would be done by Scott.

Ms RAISON - Yes, some in Launceston but all our cardiac children go to Melbourne and then come back through Hobart and then back up the State. The children who come for the hip adductors and stuff like that, they do do some of those. A doctor comes from Melbourne and he will go to Burnie and operate on some but it is not well coordinated, that is the trouble, it is just not good. So therefore they need equipment, they need

things. Often I try to send things if I can but then people have to put them on the bus and get them back to me or keep them until they come for clinic and then you are begging them. Children have to go in car seats in the car. How do you fit a child with a broken leg in a car seat?

Mr WHITELEY - Don't ask those tough questions.

Ms PUTT - I can actually remember trying to do that with one of mine and trying to figure how to stick her foot between the front seats.

Ms RAISON - That is right. I had an issue the other day with a little one in Launceston where we have a little child that is dying, a palliative baby. Because of its condition it needs to be propped up. We can do that in our hospital cots because we can prop it up onto the back so it can be kept at a level. The parents can then stand at the height of the cot to look after the baby. They are choosing to take their baby home to die. Do you think I could access a cot in the State for these parents to have at home? I found that Judy, who was a CNM on the paediatric unit at the Launceston General Hospital, was able to get me an old one for them to take home, and then we couldn't fit it through the door. So we are still trying to find some ways to resource that, but they just want to take their baby home to die.

Mr WHITELEY - But again, it's not as though you need a dozen of those cots.

Ms RAISON - No, I just need one.

Mr WHITELEY - What are they worth?

Ms RAISON - About \$2 000.

Mr WHITELEY - But it's not like we need a hundred of them.

Ms RAISON - No, it's not.

CHAIR - You were talking about the problems with transport, getting them up and back. Even if we do set up this register and we know where equipment is, is that still going to present a hurdle?

Ms RAISON - I think it could be done very much like DVA do with MacLaines out of Launceston. All of our DVA equipment comes out of MacLaines in Launceston. Down here in Hobart, if we have a DVA client, we fax DVA what we need and the numbers that correlate with the book they have given us and we tell them what we want.

Mr WHITELEY - You make an order.

Ms RAISON - Yes, we make an order and then their courier delivers it. They will either deliver it if we specify to deliver it to us and then we will go out and fit it, or they will deliver it to the house and someone will do it.

Mr WHITELEY - So a central place in Tasmania?

Ms RAISON - Absolutely.

CHAIR - So there is something in place?

Ms RAISON - MacLaines do that, but it is only for DVA.

CHAIR - That might be something that could be replicated.

Ms RAISON - Yes, absolutely. I think we need a central database and a central store so we are able to have all those things attached to that. When I was in Britain I worked in Cornwall and we had this wonderful place that was called Tremorvah, where we were able to have all our equipment. If people used equipment it all went back to this place. You get grants over there to get equipment, so if I needed a stair lift I applied for a grant and got it for the patient to put the stair lift in. When they finished with that it went back again to Tremorvah. It was given off to them, they would maintain it, clean it and get it sorted and ready to go again.

I had a budget every month; all of us would be on a budget. You might need something really new, such as an electric bed or something a bit expensive, so we would all do our shopping at Tremorvah and get all the bits we needed a bit cheaper and you would get the money on that month to get your electric bed. Next month it would be my turn to have the nice new piece, if I needed one. The amount of equipment that is thrown away, the amount of equipment that you will find in garage sales is amazing. There was a guy yesterday in the flea market in the paper who advertised a hospital bed. I phoned him up at 11 o'clock in the morning and said, 'You've got a hospital bed to give away or sell for \$50. Can we have it? How can we go about getting it?' He said, 'It went at 7 o'clock this morning and the phone hasn't stopped ringing.' I said, 'How did you come by the bed?', and he said that when one of the hospitals in Launceston was renovating he asked if he could buy one of the beds for his sick wife at the time so he could look after her at home. He wanted to pass that onto somebody else so they could do the same because it had been so fantastic for him to use.

Mr WHITELEY - People with challenges should not be immune from accountability either. Just like anyone else in society, they wanted to be treated equally. How do you make someone accountable for a piece of publicly-funded equipment? You can't rock up to a library and take a book and never return it without getting some sort of penalty.

Ms PUTT - You don't get another book.

Ms RAISON - I think it has to be the same. There should be a barcode or something like that.

Mr WHITELEY - So if you're given a piece of equipment for your sick wife and she dies, you had better be accountable to bring it back; if not, you'll pay for it.

Ms RAISON - Exactly. Do you know what the biggest accountability is that you will pay if it's not back in such a time? It is the tracking of all that. That is the hard thing.

Mr WHITELEY - But in this day of technology - 20 years ago I would have accepted that, but now there is no excuse.

Ms RAISON - No, there isn't.

Mr WHITELEY - I mean, Aurora can find us all every quarter.

Ms PUTT - But one of the issues is, for example, if someone has just lost a partner and the partner had a bit of equipment, they need a reminder to be sent from the body that has supplied the equipment because they're just not thinking right. I saw in the submission that whilst there's an issue with the equipment and the tracking of it and having a central repository of a database, and all the rest of it, there's also an issue with staffing in that there aren't necessarily always the people there who have the knowledge historically -

Ms RAISON - Not at all.

Ms PUTT - of what's where or how something has been used in the past, or whatever. So if there was a central database like that, it would actually free up staff time as well, wouldn't it.

Ms RAISON - Absolutely.

Ms PUTT - And make the staff more efficient in terms of where their energy was directed.

Ms RAISON - Absolutely. You need people with the knowledge to be able to do that as well, like the equipment scheme for the children, like the technology library where you've got Virginia McCann, who is an occupational therapist, and there is also Irene. They have people that already have the skills there as well, so it would be great if you were able to have those extra people on board when you phoned up and you needed a piece of equipment. The amount of knowledge that we pass on is incredible, like the things you say to the new grads, 'I've tried this before and it's worked. Give it a go, try it and see what you can do'.

Mr WHITELEY - Peg, we often hear, 'Oh, gee, it'd be a big job'. Well, I dispute that, in this day and age with technology. I hold 3 000 people's names on my phone. It's not hard, and maybe even if we got to a point where that database could say, 'This bit of equipment has been used in Hobart for this. Phone Robyn Sheppard, she can tell you'. A repository of knowledge is not hard.

Ms PUTT - And it can be constantly synchronised.

Ms RAISON - Exactly.

Mr WHITELEY - It can't be that hard.

Ms RAISON - I think one of the biggest things that OT Tas say is that we need to be more forward planning. We've got the basis of something there, it would be terrible to throw it all out and say there wasn't something right with the system. There are a lot of good things for people to access to be able to stay in their home. But we have to be very forward thinking. To keep people at home, to give people a life, and especially with the communication devices, we have to have another look at those, and the equipment as well.

CHAIR - Peta, I talked about the developing problems of people living longer, with obesity and diabetes. This is a situation that we are going to need to focus in on and develop plans for the future because it's not going to get any easier.

Ms RAISON - Not at all. Back to the bariatric equipment as well, with the obesity you have to realise that a standard weight on one piece of equipment is 110 kilos. My husband is six foot five and weighs 115 kilos; he is not hugely obese. People are so more occupational health and safety-wise now so they have to do it. Of course the cost blows out. A piece of equipment will take 200 kilos so, yes, the rest of the people can fit in that little square. But 110 or 120 kilos is not obese, not if you are six foot five. There are a lot of issues like that.

CHAIR - Anything more, folks?

Mr WHITELEY - This is terrific evidence, it's just practical stuff. I think we might need to come back and ask you a few other questions.

Ms RAISON - I am more than happy.

Ms PUTT - This is probably unanswerable, but I need you to tell me it's unanswerable. Obviously more money is needed for equipment, but do we know how much equipment might be out there that if we had good record keeping we could actually retrieve to alleviate the need for some of that additional money?

Ms RAISON - I think there would be some out there, but the other thing is that it changes. I got an old chair with no foot plates, but I can't get any foot plates to fit anymore. So there are a lot of things that become obsolete that are out there.

Ms PUTT - So if we started with a good database now, could we get some efficiencies in the future?

Ms RAISON - Absolutely, yes. I know money is an issue and I know it is important. I am not stupid in saying that we do not need more money, because it has been underfunded considering what it has gone from to what it has become. But on top of that the efficiencies have to be looked at - the criteria, the reasons why, what is it going to do - and I absolutely agree: having a hospital one as opposed to a community one, but they can still come under the same umbrella. You could even still join in as they have done with the equipment scheme, with the technical library with the children.

Mr WHITELEY - It would appear that the scheme has taken on a new persona compared to what it used to be -

Ms RAISON - It has.

Mr WHITELEY - but yet the funds have not grown to accommodate the community-living aspect.

CHAIR - And the rise in the cost.

Ms RAISON - That has been the enormous change from just hiring some equipment to get a few bits and pieces to tide you over, as opposed to enabling somebody who is totally and absolutely debilitated to go back into their own home with modifications, equipment and everything. You could be looking at up to \$80 000 or \$90 000 for one person.

Mr WHITELEY - I will just go back to Peg's point about the collection of stuff, with which I agree.

Ms RAISON - Absolutely.

Mr WHITELEY - I just still think - and I raised it in Launceston - there is a warehouse full of stuff sitting in people's attics -

Ms RAISON - There is.

Mr WHITELEY - and I would like to think as part of the report we could come up with some strategy for an advertising campaign -

Ms RAISON - An amnesty.

Mr WHITELEY - Yes, an amnesty. If we had a repository to get it to then people like you could make a decision as to whether it could be utilised.

Ms PUTT - We need a drive to get it back and you would have to assess which stuff is worth keeping and which is not. Then you would have to get blokes like these from TADTAS to come in and have a bit of a go if it needs just a bit of tinkering.

Mr WHITELEY - Service clubs, I am sure.

Ms RAISON - If you had an amnesty to say there was no fine to pay or anything, we just need to have this back, I think it would be a good idea.

Mr WHITELEY - Probably half of it would be okay.

CHAIR - It is starting to sound like a brainstorm session, which is very good, but we have somebody waiting. It was very interesting, thank you very much. We appreciate your evidence very much.

THE WITNESS WITHDREW.

Mr DERRICK HARNWELL, SPEAK OUT ASSOCIATION OF TASMANIA INC., WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Finch) - Thank you very much for taking the time to come and appear before our committee. I suppose you understand the terms of reference that we have for this report. We have had some really interesting submissions made around the State. This is our third port of call. We will be interested to hear what you have to say and if you would care to make your submission to us and then we will ask questions following on from that.

Mr HARNWELL - Funding is one of the biggest issues in terms of equipment. As an advocacy service we come across people every day who are trying to get equipment for themselves, family members, relatives, whatever, to help them live independently or just have a reasonable quality of life. It is just becoming more and more difficult as an advocacy service to give people any good news about access to equipment, and equipment may be the simple necessities such as a wheelchair or electronic wheelchairs. One of the biggest problems is that electronic wheelchairs currently are about \$15 000 to \$20 000 to purchase. People are making funding submissions to try to get a new electronic wheelchair - they have outgrown their other one. Obesity issues and things like that are a problem with people who are non-ambulant and putting on weight and every two or three years they may require a larger wheelchair. They may have moved house and their new house does not physically allow them to move around in their old wheelchairs. People are being asked these days to fork out \$15 000 to \$20 000 to purchase their own electronic wheelchairs because even if they put in a funding submission to \$20 000 to purchase their own electronic wheelchairs. People agree that OTs, physios and seating clinics are involved and everyone agrees that this person needs a new wheelchair, yet the money just isn't available to purchase it. That is one of the biggest issues I am finding at the moment.

CHAIR - Can you explain about the Speak Out Association of Tasmania? Can you tell me something about your organisation?

Mr HARNWELL - We are a member organisation so we advocate for people with intellectual disabilities. We have members who pay a membership fee each year to be a part of our organisation. We advocate for people across a broad range of issues: accommodation; housing; dealing with services such as Telstra, Centrelink, your good selves; people who have to go to court because of misdemeanours, restraining orders et cetera. Anyone can give us a call, such as staff who work with someone with an intellectual disability, the person themselves, a family member or whoever who has found that they can't access a laptop computer for their daughter with dyslexia who would like to study at a TAFE but isn't able to access the software packages to enable them to have voice-recognition software on the computers. They may give us a call and say, 'We've spoken to numerous people and we aren't getting anywhere. Can you jump on board and help out?'. We liaise with Disability Services primarily, but also services such as Centrelink or occupational therapists at the Repat and things like that.

CHAIR - How are you funded?

Mr HARNWELL - Half by Federal Government and half by State. There is also a fairly minimal amount from our membership fees from our members.

CHAIR - You were going to talk about computers.

Mr HARNWELL - A client I had recently wanted to do a child-care course and was very motivated and enthusiastic to further herself educationally. She was coming in on a public bus from Franklin to Warrane every day. She had to get the lectures transcribed and would then have to go home and sit down with mum and go through all the transcriptions. It was decided that probably the best alternative was for her to be able to use the time she was travelling from Franklin to Warrane to have her own laptop and have some voice-recognition software on it where she could directly transcribe straight into the computer during her lectures. Once again, there was absolutely no funding available for her to purchase a laptop computer or to get software packages that would enable that to happen. They had it at the TAFE, so she was able to access the computers at the TAFE college, but she was basically wasting two-and-a-half hours each day travelling and going home exhausted at the end of the day to have mum sit down and transcribe everything for her. She would then have to put it into a computer at home. That was a big problem.

With the wheelchair issues, I think there are always ways you can get around it. Sometimes we have benefactors who might put some money towards it. Something like \$15 000 to \$20 000 for a wheelchair that enables people to access their community. We now have quite a few wheelchair-accessible taxis and things such as that so people are more able to get out and about, go down to the casino, see a band or whatever. However, if they don't have that primary facility of having a working, electronic wheelchair, then it all falls apart.

Mr WHITELEY - And service clubs can only hold so many functions. They are all doing a great job.

CHAIR - How many clients would you have with needs that are relevant to our terms of reference?

Mr HARNWELL - We would deal with maybe four people in a year who contract us and say that they have applied for funding. Are you talking specifically about wheelchair issues?

CHAIR - Not just wheelchairs but also to equipment - assistive technology.

Mr HARNWELL - Probably 15-20, if assistive technology includes tracking in bathrooms and things such as that.

CHAIR - Do they come to you as a last resort?

Mr HARNWELL - They are the ones that actually contact us. A lot of people give up hope when they are initially told there is nothing available and no money available. They know that we can provide a service that assists them with that. However, at times, as I say, you become a little bit disillusioned with the system when you are repeatedly going to Disability Services trying to get one-off funding for equipment and continually having them say it has merit, however there is no money available.

CHAIR - Is that what you have found, that your success rate is very low?

Mr HARNWELL - Very minimal, yes. I was listening to lady before me talking. At the time that I was dealing with this client who was not able to purchase another wheelchair, I had another client who had died over the Christmas period and who had a perfectly good electronic wheelchair but his mother did not know what to do with it. She had no way of finding out whether she could donate it to someone or sell it to someone or something like that. It may have simply been a matter of changing the seating arrangements and things like that to suit another person. So maybe its about advertising for people who have some equipment that is sitting in the garage or not being used or whatever and being able to share it around.

We also understand that a chair does not suit every purpose. So there would have to be the modification expertise available in Tasmania, which it just is not at the moment. I have heard that there is no manufacture of electronic wheelchairs in Australia these days. Everything is coming from the USA so any spare parts or any modification that are required are having to come from the United States. So if you are reliant upon your electronic wheelchair to get around, waiting for four weeks for parts to come from the United States can be really difficult. You are reliant then upon using a manual wheelchair and having a support person or family member or someone to push you around, which can be really tough for people who are used to that independence.

CHAIR - Are getting this insight into the situation that it needs to be rectified and something needs to be done to get more funding?

Mr HARNWELL - Absolutely.

CHAIR - Because you are seeing too many at your end who are at the last stages before they give up, I suppose.

Mr HARNWELL - Other people have other advocates as well. They might have a family member or a friend who can advocate for them. So we would not have contact with them. It is only the people who have nowhere else to go who may use an advocacy service or who do not have living relatives or a friendship network to support them in that.

CHAIR - So what are the general messages you get when you try to access disability services or try to solve these problems? What are the observations you are able to make from those discussions?

Mr HARNWELL - Good people in disability services up against the same difficulties and issues that we are. If the money is not there, then the money is not there. You cannot rely on people's goodwill, especially where you are talking about large amounts of money. You cannot rely on the goodwill of a next-door neighbour to do up a car or something like that and it may only cost \$1 000. These are very specialised pieces of equipment. So I do not have a problem with disability services. I guess they can only work to the budget that they have and unfortunately it does not seem to be covering these areas. You get to a point where family members do try to fix up someone's wheelchair for them. They get a mate who is a welder to come over and all of a sudden you have occupational health and safety risks to staff members. The client that I am talking about

here was going to lose his placement at his day service because they considered that it was too much of a risk for their staff to be supporting this person because his wheelchair was not up to scratch. They did not want to, under their own policies of occupational health and safety, support this person out in the community with his programs.

Ms PUTT - So there can be a knock-on effect to all other participation?

Mr HARNWELL - Yes.

CHAIR - Where did TADTAS say that they received their references from? The general public, the community or somebody like that?

Mr BEST - I think that they said that they sat outside the standard things. They would not repair chairs for an organisation but if someone came to them with a special need for a chair, then someone would design something because that is the volunteer base.

CHAIR - We heard from an organisation that provided technical aids for people with disabilities.

Mr HARNWELL - I think they're very good on your small manual wheel chairs and things like that, however the larger electronic wheelchairs are fairly complex. The battery system weighs tonne. If you are half-way up a hill and your battery system conks out then you are in real trouble. It can take four or five people to help you get to a safe place in those wheelchairs.

CHAIR - Thanks for your time.

THE WITNESS WITHDREW.

Associate Professor CHRISTOPHER NEWELL, SCHOOL OF MEDICINE, UNIVERSITY OF TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

Assoc. Prof. NEWELL - Firstly, I want to address some of the substance of my submission but also in light of the other evidence and submissions that were received. You will see that the submission I give is a little bit different because it dares to ask, 'What is disability?' That is a profoundly important question. It is a question with regard to technology because often we think of technology and adaptive technology as something that is about those people with special needs. We think, 'Thank God, I don't have a disability'. Disability is about the other rather than the us.

The evidence I am giving is based not just upon the experience I have living with disability. I am a researcher at national and international levels in this area and I have received a variety of awards for that work. Just coming into Parliament House, you immediately become aware of special needs because you have wheelchair access. It is most convoluted, rather than the access that is taken for granted by most members of the Parliament, I think. That immediately turns people into special needs. It is the technologies that we have that reflect our social values. The technologies say what is nice, normal and natural. We have adaptive technology, special technology, largely because we have not gone in for universal design. There is a significant body of literature that covers universal design and speaks about that.

I did masters work 20 years ago now into telephony and equipment schemes. I can remember concluding even then that what was needed was a universal approach. These days what is very fascinating to see is that, whilst a variety of players have adaptive technology, the technological approach that really wins is the approach that recognises that we need to design for everyone. The first thing I would suggest is that there needs to be the fostering of a design for everyone via universal design, and then only when you need special needs or only when there is an exception. It always happens. Do you need to have adaptive technology? The US, for example, has done this with section 501, which requires that publicly funded buildings and so on be accessible for people with disabilities. There is a significant buying power associated with the US Government saying, 'We require under section 501 that all technologies be accessible'. That has profoundly influenced the way in which technology is designed. It has lessened the need for retrospective adaptive technologies. The US has the advantage of taking that national approach. Whatever you do, I would suggest that in Australia we need to be working together on these sorts of things rather than yet again having different schemes with different formulae. We can't seem to work together even in terms of having similar criteria that enable people to be Australian citizens, let alone global citizens.

I have also emphasised 'What is disability?' because there is a profound thing troubling me at the moment with regard to this whole inquiry and that is that you are just biting off a little bit of this enormous area. The area of disability, I have suggested in my submission, requires a royal commission and nothing less. I have also suggested that one of the commissioners should be a person with a disability. The reason I have suggested that is that we have inquiries time and time again about people with disabilities where we talk to people as the 'other'. Usually, concerning people who give evidence, a variety of people go away thinking, 'Thank God I do not have that' rather than, 'Thank God for that wisdom' and how we need to inject that into our public life so that life is accessible for

the most disabled as opposed to them being an awkward moment that we get over quite quickly. In thinking about the technologies that we have my suggestion is that there is an urgent need to look at the way in which we create this ability in this State and that the technology is one of the subsets of the things that need to be tackled in terms of enabling Tasmanians with disability.

Mr BEST - Are saying to look at how we create disability?

Assoc. Prof. NEWELL - Absolutely. There is significant literature in disability studies that looks at the fact that people live with impairments, but whether or not they have a disability really relies upon on how people function within their social environment. That is where norms actually come into play. Now, the reason why you should not pay any attention to me is that I failed at school - because I had inflexible learning system. I had the joys of working in a sheltered workshop, and still cannot stand KFC to this day because we used to package the little refresher towelettes. That was the pinnacle of my existence - or was it? I was assessed by the university of Tasmania, where I now teach, as not being worthy of being admitted to a degree program, and then paradoxically a couple years ago was made one of the distinguished alumni of that institution. You could dismiss me quickly because I am a very disturbing witness. What actually enabled me was a flexibility of approach in education. I still rely significantly on a whole heap of technologies to get me through the day, for personal care and those sorts of things. Unfortunately, I have given up trying to use the public system. I would love to be able to use it. You have heard of sexually transmitted debt as far as divorce is concerned, well it was also the case with disability when my wife married me. My wife was a carer, and stereotypically we fell in love, or she said needed a challenge. She married someone whose technology bills last year were about \$20 000.

Now, I think these days I am contributing significantly to the country and to the State but there is no assistance and there is no recognition that the basic functions in life that people take for granted are for me like living. I use an oxygen concentrator or a variety of things for my respiratory disabilities, and wheelchairs and these sorts of things should be basics that the state attends to. They should be basics that the state in political economy terms attends to because they are about helping people, firstly, to be all that they can be as citizens. Secondly, it is not about giving preferential treatment to someone; it is just about addressing an account of justice that means that all people have an equal outcome as far as being able to do the basic functions of life so that they can then go on and do education and employment and a variety of things.

Mr BEST - When you say as a 'basic' there is a whole new area that we have not gotten to, and that is a flexible approach to assist someone to do the things such as learning.

Assoc. Prof. NEWELL - Yes, and I noticed the ACROD submission did name this. The equipment scheme that we have at the moment is largely based upon the biomedical model. Here is where I recommend my book, *Disability in Australia* - one always has to refer to one's own work - which won the Human Rights Award in 2005. That book looks at the way in which society 'makes' disability. Society either sees me as someone who was dependent upon an invalid pension - I went onto an IP when I was 18 - or it says you are actually a highly valued contributing person with the appropriate technology. That is what I mean by the social model. The social model also recognises that we need to assist people to overcome the disabling nature of society. I talk about a 'disablist' society. We

have talked about sexism, we have talked about racism in society. I would suggest to you that our parliaments have yet to address substantially the issue of disablism, the fear of disability, the fear of difference that inhabits all human beings. Rather than being a central issue with regard to at least 20 per cent of the population, it is mostly tackled by the awkward moments on the front page of the *Mercury*. We then have a ministerial one-off solution and then we move off until next time disability as an issue on the front page raises it. We should never, ever, ever have to have an approach like that. That relies on the charitable account of disability. We need an account which looks at the fundamental rights of people, and I would again commend to you the Universal Declaration of Human Rights as having some of those goods spelt out. Then there is the Convention on the Rights of People with Disabilities recently proclaimed by the UN, again a very important instrument.

Ms PUTT - We had another witness who talked to us about our language, who said we should be talking about people with differing abilities -

Assoc. Prof. NEWELL - Yes, I read that.

Ms PUTT - That was really important. I can understand that I have differing abilities to other people and we can all understand that, and that includes us all, rather than creating a category of 'other'.

Mr BEST - Differing abilities.

Ms PUTT - I think that was behind her thinking, and you might want to comment on that. The other thing that I just wanted to ask you about and I am glad you came around to the Universal Declaration of Human Rights because what I was going to go to was whether therefore in connection with this we need to be looking at a Charter of Rights for Tasmania.

Assoc. Prof. NEWELL - You have raised several very interesting issues. I think I would be reluctant as a witness to chastise you as members of the committee for your language. I think that the witness was probably trying to emphasise differing abilities. The problem of course with the language, people with different abilities, is that you end up having to ask 'different from what?' and so what it leaves unexamined - and I have explored this in my scholarly work - is the normative dimension - that is, different from the normal.

Ms PUTT - As opposed to just different from each other?

Assoc. Prof. NEWELL - Yes. You end up with is this category that I would call the 'euphemistically named other'. We will try desperately hard, and that is why I talk about people with disability. Again I refer to that in my publications. I talk about people with disability rather than saying 'people with a disability'. That is in terms of a biomedically defined account, but 'people with disability' is really a socio-political space. Sorry, I do not mean to get too jargonistic but it recognises that disability is a category created by society in the same way that largely race as an account of difference is. We are still coming to terms with what we mean by being indigenous and how we respond to those categories. We do use categories. I think probably the really big issue to do with this is using language that helps us to address the injustices associated with the creation of category of 'other', and it is that 'othering' which is profoundly problematic and is

reflected, I would suggest, not just in technology but also in social programs. I used to propose and I still believe that we should have an aim in any social justice document to envisage a person with a severe speech impediment being able to become the Premier of this State. Then we should ask what we need to do about our disability strategies to address that. Not in a way that says they are special people, but if we can imagine a woman being premier and if we can imagine a person of Aboriginal origin being that, why cannot we use the power or narrative to think about how we can imagine a person with a disability being a premier. All of a sudden you would say that of course we will need a variety of accounts of technological assistance for someone to do that. Rather than saying that to have a communications device is a special need we would say that is what you need to enact your basic human right, and go about doing it.

Frank Bow, years ago wrote a book called *Handicapping America*. He looked at how much it cost America to handicap Americans with disability and then he wrote a book called *Enabling America*. In the current environment where we are very close to full employment in some areas, I suggest that we need to, in a Marxian-type sense, look at disability in terms of a lumpenproletariat. We need to understand the Reserve Army dimension of that. We need to say that there are a lot of people who could be enabled via the appropriate use of technology and, rather than talking about people having to prove every day how pathetic they are in order to get benefits, perhaps we could help people to imagine how wonderful they are and how much they could achieve in life.

Once upon a time I knew I could not get a degree or be anything. I am very grateful to some of the people who helped me to know otherwise and for the technology to help me to be that way.

Mr WHITELEY - The crazy thing about that, Chris, is that if we were to move that way so that someone like you, can earn an ordinary salary, the money that we currently pay someone in a disability pension, one year's worth of that would probably be sufficient to provide the enabling assistive technology. It is an irony that I cannot quite get my head around. It is an investment isn't it?

Assoc. Prof. NEWELL - It is an investment. One of the problems we face here of course is the cost-shifting problem. Disability and the State, Territories and Commonwealth do an annual argy-bargy about this, rather than saying it is in our collective interests as part of the common weal. What does it mean to be part of the Commonwealth? And, to explore what I think is an under-explored dimension of political economy, and worthwhile for our parliaments to explore, the common weal applies to people with disability as well.

I was very sympathetic to the explorations of a bill of rights. I was profoundly disappointed with the quality of the report that came out of the University of Tasmania. It was not that the disability community did not know that the inquiry was on, but I think the best use was not made of the disability networks to get optimal input into that inquiry, and that was also disappointing. As a consequence, rather than exploring what specifically would be needed to be done to enact the rights of people with disabilities in the same way that a variety of other social groupings were explored, the report was quite agnostic; it did not mention it specifically. We know from a variety of experiences. We have the Disability Discrimination Act but we still have discrimination. We have the Anti-Discrimination Act in Tasmania and yet we still experience discrimination. It is only when you do proactive things as well. So my profound disappointment is the lack

of engagement, including the fact that nobody bothered to talk to me and I am by far the most-published researcher on disability in this State.

CHAIR - This comes back to a point you made here in point 17, that people with disabilities should be on boards of management, allocations schemes - any schemes State controlled or NGO. We have already heard evidence here today by Ms Robyn Wilkinson who was saying that people with disabilities should be included on boards and committees that do investigation. She clearly has not been included and here you are saying exactly the same thing.

Assoc. Prof. NEWELL - It may be deemed that I am not qualified. I have six degrees and two professional fellowships and I have over 300 publications. One of these days I might be qualified.

I think Ms Wilkinson, as ever, makes very important points. May I commend the wisdom of Ms Wilkinson, who is a rare gem in the Australian scene.

CHAIR - It puzzles me that she is not included and doesn't feel included.

Assoc. Prof. NEWELL - To be honest with you, I tried to engage with the Department of Premier and Cabinet over disability matters and I gathered from a letter from the Secretary of DPAC that I wasn't really qualified either. I am hoping one of these days to be. The interesting thing is with people like me that we tend to go interstate and provide advice and sit on boards. For me, that is rather sad.

Mr BEST - Would you say that, compared to other States, our State probably has some very pre-eminent people with skills with disability who could comment, advise or provide specific information that we could benefit from but that we are not harnessing?

Assoc. Prof. NEWELL - Yes. Having explored disability in terms of other States and also a variety of other countries, my suggestion is you have a very few people with disability who are really quite extraordinarily competent. There are a few of us around, largely hidden or not feeling that their voice is all that welcome in a variety of places. To live with disability is to be a profoundly discomfoting figure to a lot of people still, unfortunately.

The disability rights movement in this State has become exceptionally good at being disabled as opposed to really enacting what it is to live with disability in terms of claiming human rights. There is a lot of work that needs to be done in community development - that is, helping people to be all that they can be. That needs a lot of peer work done and there are a lot of excellent examples of that occurring. It is not just a matter of sticking a token person on the board, you really need to be doing some development with people. There is a significant problem in this State in terms of people without skills but it is quite possible to develop skills within organisations and mentor people. Women 30 years ago were upping their skills and claiming a place, but it helped to have some funding as well and to have purposeful programs that did that. It also helps to have objectives to do this. I didn't mean to sound as though I had a complex, but I think probably what has happened has been that the awkward voices have not been welcomed in a variety of places. I think we have had an impact. I can remember talking to DPAC about a human-rights approach to disability which informed the strategy they

have now, but I think the cost, frankly, was a feeling that I was a very difficult customer in that I wanted too much. All I want for people with disability is what any other citizen should be entitled to. So the need is for some purposeful work and some dollars, but the return will be enormous.

Mr BEST - Return in what regard?

Assoc. Prof. NEWELL - Social and economic. That is a problem again. Largely we tend to actually account for the cost of disability by Commonwealth pensions or State disability services but what we need to do is meld the State and Commonwealth stuff and come up with an account of economics which moves beyond the neo-classical, quite narrow account to really encountering some of the accounts of what is now being called social capital. I say that not in an ideological sense. If you think about, for example the education that you received in life I think that you could claim that there was a variety of non-economic benefits associated with that. Then of course the biggest education I probably had in my life is to have had the privilege of being married and having a family. And as someone with a teenager I can tell you I am still receiving an education.

Laughter.

Assoc. Prof. NEWELL - It is very important because I spent most of my life in hospital when I was growing up so I failed at school et cetera. But I learnt a lot of things because I was living with my own mortality. So I have suggested a life-cycle approach.

Mr WHITELEY - I saw that; I noticed the footnote so am I am going to go and have a look at that.

Assoc. Prof. NEWELL - Things are appropriate to people in different stages of the life cycle. It is about doing things smarter and more intelligently, not holding people back. But in terms of resources allocation you are going to have to do something.

Resources allocation - and I love teaching this with medical students - you will never have enough money so you will always have the need to do resources allocation. It does not matter how much salary you have, you have to do rationing every day and you do it, I think, according to some pretty good virtuous practices. So there are values that we have that are largely understood even if not spoken that can guide us and, as I suggested there, the virtues of wisdom and justice and love. That is an account that is not just about myself but actually a transcendent account. You might say we cannot do anything to do with love but, if you think about it, just about everything we do that matters in life actually involves love, one way or the other.

It involves an agapaic dimension to life, not the eros that we are told about in the ad campaigns. If you are doing your resources allocation, my suggestion is that you need some very clear values and you need a process that involves people in disability, including an account that suggests that they have some expertise. For models, look at the work that is being done by the Consumers' Health Forum of Australia, in terms of consumer participation in a variety of high-level committees, including for example the Medical Services Advisory Committee which deals with very specialised type of areas.

You can take people and use them in a way where their life experience is a positive rather than being seen as something negative, with no inherent value. The real challenge with anyone living with an impairment is not so much how much they cannot give us but how much we are prepared to allow them to give us. We think that living with Down syndrome is so bad but if we talk to someone with Down syndrome we encounter a very different account of life, which suggests that many of the approaches that we base on intellectual achievement are quite superficial. I reflect on that often in a university environment where we tend to think cerebrally all the time and yet there is probably more wisdom in the lifestyle that some of my friends with Down syndrome live than some of my colleagues whose academic success seems to be proved by how many marriages they are now going through because of the disproportionate emphasis on one thing at the cost of other things. I think I have told you about academic life as well, I would say.

Laughter.

CHAIR - We have touched on a few different areas haven't we today.

Assoc. Prof. NEWELL - But when we touch upon a variety of things we are touching on what it is to be a person; that is why we talk about 'people with disability', the people-first language. The New Zealanders and the UK have said 'disabled people' because they want to make the point that it is society that disables people but I think overwhelmingly in Australia it is the 'people with' terminology. It is probably the end bit that is the highly contested bit. I think 'euphemistically challenged others' probably works but may not be politically correct.

Laughter.

CHAIR - Is that our last thought for today?

Ms PUTT - I was going to thank you. In your submission you are drawing together a number of observations that we have had made to us from various people but you are starting to put it in a context that is really helpful.

Mr WHITELEY - In a values context.

Ms PUTT - Yes, that is right, in a values context, but also looking at things like a centralised system or State or non-government control and all the rest of it. And it is about this issue of different levels of government. The temptation is to think they are big stumbling blocks and we will not look there, we will just look at this little subset. I thank you because your submission will make sure we do not just do that.

Assoc. Prof. NEWELL - I wish you well with it. The problem of doing this, of course, is that you will never be able to do it to the satisfaction of everyone. I tried to give you more dispassionate recommendations. I think as a scholar I should give you something that is not just about my own self-interest. Some of the recommendations are not going to benefit me directly but I would suggest to you that they are recommendations that would help you to shape something that would help people to be all that they could be, that would truly help with enabling people.

Also, I tried to be reasonably agnostic in terms of a private provider or State provider -

Mr WHITELEY - I noticed you said, 'If you did go that way' -

Assoc. Prof. NEWELL - The disturbing thing is, and one of the challenges is, whether any providers have people with disability on the boards.

Mr WHITELEY - That's right. No.

Assoc. Prof. NEWELL - From my conversations with a couple of CEOs, I think they are sympathetic to the idea but somehow it never happens and, again, it is about building capacity. If you do not want to have people on boards you have them on advisory committees with requirements that those particular committees be given due weight. There needs to be something in funding agreements that you do that.

Having said that, I would not give up on the State being involved one way or the other. What we see is because of the dominant counts of disability we tend to focus on people with disabilities costing too much and being a burden and that means that inevitably the market really struggles with this. We have seen already that market solutions to disability work for some clients but for those who are seen to be too expensive it is always the State that has to pick up the cost.

My desperate mission in life is that, before I die, not just people with disabilities but all people will feel embraced by society and will be enabled via the proper provision of support such as assisted technology to be all that they can be.

Mr BEST - Chris, as an explanation, the committee did deliberate for quite a while about what our terms of reference would be and we decided that equipment was really what we could manage.

Mr WHITELEY - That was the reference that was brought.

Mr BEST - We thought it would be great to get into all this. At the end of the day we have to do something that we can get a report on otherwise we could spend years - which is what it needs; I do not want to sound like we are doing it an injustice in itself but I wanted to explain that.

The other thing I was going to say is touching on those principles which you mentioned about love, wisdom and justice and those things - the virtues.

Assoc. Prof. NEWELL - Sorry, my training in the area of ethics is coming in here. The virtues are not just old-fashioned, they are lived out every day.

Mr BEST - You have a view then about how many things, apart from this one particular reference, if approached appropriately or correctly, could help people to be all they could be. There could be a whole range of quite amazing things that could develop from this State I suppose -

Assoc. Prof. NEWELL - Absolutely.

Mr BEST - that could lead to other things elsewhere.

Assoc. Prof. NEWELL - I would encourage the committee, as I dared to in my recommendations, to think outside the square that you created for yourself and suggest that it is properly the domain of this Parliament to think about the significant section of the population that is disabled and to think about how we are going to enable those people who we call people with disability. My suggestion also is that parliamentary processes can be exceptionally useful for shaping an opportunity for people to speak for the wisdom that ordinary people and scholars and policy makers bring to such a table. I also suggest you think about the charge that is properly yours in terms of a parliament which is elected by the people to enact the principles of a democracy.

Democracy is not just about the majority rules. It is about the proper provision of the goods of life and especially the basic goods of life to enable people to function and to thrive in society. So that excursion that I have is probably, if I might suggest, the disconnection that we have. We talk about disability over here and then we occasionally talk about what it is to have a society and what it is to have a good life. My suggestion is that we need to bring disability and an account of the good life and good society together and that disability just is part of the social fabric. We should be recognising that, and thinking about the decisions we make every day that either disable or enable.

Mr BEST - Thank you.

CHAIR - We have gone over time. You have successfully gone over time, Christopher. I sense there is more where that came from.

Assoc. Prof. NEWELL - That is why I write books.

CHAIR - Christopher, thanks very much for your time, we appreciate it very much and hopefully we will do your submission justice when we make our observations as well as our recommendations.

Assoc. Prof. NEWELL - I would hope so. I did mean what I said in that I really struggled with engaging with government at the State level. Yet I sit on the National Health and Medical Research Council and I am a commissioner with the Safety and Quality commission at a Federal level, and not just because of my good looks.

I believe that there is so much potential in people and I wanted to see that lived out, not for my own benefit. You can see there is a deep ethical reasoning associated with what I do. It is not just give me, give me, give me. You will find that with anything that Robyn has said to you. Robyn is such a wise person who should be the State's disability adviser.

CHAIR - If nothing else, this inquiry may enable those messages to in fact have a wider audience and that you people, Robyn and yourself, gain some recognition in the role that you could play even more strongly in the community.

Assoc. Prof. NEWELL - Thank you very much. My latest book that I have released this year is on human rights education, and how to use the education system to deliver on human rights.

Ms PUTT - It is fascinating and obviously extremely important.

Assoc. Prof. NEWELL - Again, that is my old-fashioned account of what it is to be a scholar.

Ms PUTT - It is interesting to me because I have a brother who is profoundly deaf and I talked about this some other time. I have got him a phone that he can text messages with. So he and I now have an avenue of communication that we have never had before.

Assoc. Prof. NEWELL - It is a very interesting colonisation of a technology by the deaf community. What is based on aural values is now being colonised by the deaf community in the same way that TTYs were a once-discarded form of Baudot code - an old technology that they literally received from the dumps in the USA and they reconfigured it for themselves and used that. That is a really interesting use of technology by cultures and a very cross-cultural thing.

THE WITNESS WITHDREW.