THE PARLIAMENTARY STANDING COMMITTEE OF COMMUNITY DEVELOPMENT MET AT HENTY HOUSE, LAUNCESTON, ON MONDAY 28 APRIL 2008.

INQUIRY INTO ASSISTIVE TECHNOLOGY AND EQUIPMENT FOR PEOPLE WITH DISABILITIES

Mr MICHAEL SERTORI, CEO AND **Ms CATHERINE MERRY**, ALLIED HEALTH MANAGER, ST GILES, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR (Mr Finch) **-** Thanks very much Michael and Catherine for joining us here today. I think we have an understanding of who you are, Michael, CEO of St Giles - legendary of course.

Mr SERTORI - I have to agree as I have just agreed to tell the truth and nothing but the truth!

Laughter.

CHAIR - Catherine is the Allied Health Manager with St Giles and has been for many years. Michael, you must have been there 12 years?

Mr SERTORI - No, 14 years.

CHAIR - Time flies. Thanks very much for your submission, but we are pleased to hear from you today. We are happy to hand the floor over to you so that you can present whatever you wish to highlight and then we will ask questions of you. We will go to the terms of reference, too, before you depart. I just note that the time is 11.15 a.m., so we have cut into the time available to you; however we will still take 30 minutes. We have a cancellation so we have some latitude.

Mr SERTORI - Firstly, congratulations to the committee for this very timely and important inquiry into a vital part of Tasmanian life. As you know, we have provided a written submission and I thought we would just highlight a couple of things from that submission today. It might be useful to start by just noting some background of St Giles relevant to this inquiry. I know some of you are very familiar with it, but other members of the committee may not be.

The services of St Giles that are relevant to this review are as follows: we operate the statewide seating and equipment clinic and there are some brochures available to the committee to explain what that does. We also operate our own equipment loan library. We run a paediatric therapy service which supports about 1 600 children, predominantly in this region. We provide direct client funding for equipment and of course we operate the annual *Examiner*-St Giles Equipment Appeal.

Just in case there is any possibility of a perceived conflict of interest, I note the following. The seating clinic operates statewide and we have an annual turnover of about $700 000. It operates on a break-even, not-for-profit basis and we support about 500 clients. We are exclusively contracted to support MAIB clients across Tasmania. The clinic, which has operated for about 16 years, does not receive direct government funding; it relies on cost recovery from client fees. Through our fund-raising activities in that time we have invested about $5 million in capital development infrastructure to get that clinic off the ground. Our equipment loan library has invested around $500 000 in equipment assets and in any year in addition to all of our fund raising we have provided up to $250 000 in direct client funding. So there are some business interests we have in the outcome of the outcome of this inquiry.

I want to touch on a couple of national developments which you may not be familiar with. I know from other submissions to this committee that you are aware that during last year's Federal election campaign we sought to extend the Australian Medicare scheme and that was to cover the gap in the cost of specialised equipment for Australians living with a disability. We noted that in the USA and the republic of Ireland - and, we understand, the UK - their respective health schemes fund accessible equipment for people with disabilities.

CHAIR - We feel a trip to Ireland coming on!

Laughter.

Mr SERTORI - Having been there and knowing where to go I might need to guide you. I know how you can get led astray!

Laughter.

Mr SERTORI - It was our view that if we could adopt the practice in Australia of being able to claim under our national health scheme it might provide people with disabilities a more dignified pathway to funding their needs against the current system that sometimes requires somewhat innovative and undignified fund-raising pathways. We did receive 70 per cent response to our delegations and we did write to every member and every potential member of the Australian Parliament. What we hoped was that at least it would focus the debate on a national response to funding equipment needs.

Since then there have been several developments. We understand investigations have advanced into establishing a national disability insurance scheme to fund now non-compensable individuals needing long-term care as a consequence of a catastrophic injury and I am delighted that that idea was projected recently at the 2020 summit in Canberra. I believe it is an idea that has growing political and bureaucratic support, particularly in Federal Treasury. Unfortunately it will take years to establish but, once established, it may well take pressure off State schemes, particularly for people with disabilities.

There is some interest in establishing a national equipment scheme for people with disabilities and that is at fairly early stages. The Commonwealth State and Territories Disability Agreement is at the moment subject to renegotiation and I think has been deferred. We hope submissions that we put through various bodies will be accepted to include negotiation of funding levels for equipment needs for people living with a disability and, indeed, perhaps consideration of extending the Medicare scheme.

Those, as we understand, are some of the things that have occurred at a national level, all of which are focused on trying to take the pressures of the States to fund their respective schemes.

Turning to the Tasmanian community equipment scheme, which is of interest to this committee: we firstly looked at the proposition of 'aint-broke-don't fix it' and we looked at all the things that we might not change and we came up with a very short list of one item and that related to the current priority ratings that we believe are appropriate under the scheme. Otherwise, as I said, the list of what should change is fairly long. We believe the scheme is in need of a major overhaul and perhaps, on reflection, should have been highlighted as part of the terms of reference for the recently conducted KPMG review of the disability sector.

We have put our written submission to you but I just want to highlight a couple of things. Firstly, starting with funding, let us look at the Government's guidelines and criteria. In our submission the current levels of funding and its allocation and distribution are totally inadequate. Tasmanians living with a disability, as we have noted in the submission, experience the lowest level of funding per capita in Australia and, indeed, Tasmania's funding is well below that of any other State and Territory, well below. In looking at that we make the following observations. Funding levels have failed to keep pace with inflation and the rising cost - and, in some cases, the sharply rising cost - of equipment and technology and therefore funding has declined in real terms. We note that most equipment is relatively expensive due to the fact that it has to be customised and specialised and there are low production levels. It is some time since there has been a meaningful increase to the scheme - noting, however, that the recent $800 000-plus injection is just starting to have some impact in this region.

The number of people accessing the scheme has expanded considerably which is affecting the level of funding available to people with disabilities and it is certainly affecting their priority level in trying to qualify for funding. These circumstances have been compounded by the number of people exiting our hospital system. These people have consumed not only funding but also priority under the scheme.

Ms MERRY - I can give examples there in terms of a more practical level. I sit on the northern community equipment scheme panel and we have approximately $6 000 per month for the entire region to disburse. New applications could be up to $100 000 for that month, but we have $6 000 to distribute, and that is for the entire region and it includes children, people with disabilities in the community plus people who need to be discharged from hospital. Also the big push to discharge people early means that they need more equipment in order to get home.

So if there is one person, perhaps, who has had a major stroke and they need to choof them out of hospital as soon as possible, that is all good but they might need a pressure care mattress -$2 000; electric hospital-type beds so that the partner can move them around, sit them up et cetera - $2 000-$2 500; a special commode - up to $1 200; and a wheelchair - probably up to $2 000. After getting just that one person out of hospital there is not left with that month's CES allocation and that is not an untypical course of events.

Mr SERTORI - Thank you, Catherine. There is also growing demand in the scheme through the increased rate of disability in our population and, indeed, we are seeing the first experience of increasing longevity of people with disabilities in our community, particularly those with very complex needs.

Ms MERRY - Again, we think about a number of clients that are in shared homes that our organisation operates. Perhaps many years ago those cerebral palsy, wheelchair-bound clients would not have survived to this age, but now they are in their mid-20s and 30s. The ageing process sort of kicks in a little bit earlier with these people and what we find is that in their mid-20s they are subject to a lot of pressure issues. We certainly need to address that, otherwise they are going to take up a hospital bed for quite some time, and their entire care needs become far more complex because of those issues. Therefore the appropriate equipment for their needs goes up a little bit in the cost side of things because it is the quite specialised equipment. So this is becoming a feature of a number of the clients whom we see, particularly through seating clinic, and who are coming back more regularly. Again this relates to the KPMG report in terms of the services to that group of people in the post-18 group. They are getting quite a bit of attention through our therapy service while they are officially in the child category but post-18 those supports are not there and yet their needs actually become greater. So there is quite a discrepancy in terms of what is available to them.

Mr SERTORI - As is the case for all funding of disability in the State, as far as the scheme is concerned there are enormous inequities between regions. We also believe that the administrative management of these systems contributes to effecting this inequity, and particularly in the response times to funding applications. We do not choose to make a submission on it, but some of the propositions we have had put to us about some very strange administrative arrangements are, if true, totally unsatisfactory and unacceptable and need further inquiry. But we would like further evidence before we are prepared to make the further submission on that point.

We have certainly grown weary of the constant battle in trying to secure funding for clients. We are frustrated with the inconsistent governance, the compromised prioritisation arrangements, inconsistent treatment of standard and non-standard equipment, the need to pursue political interference to achieve funding, inconsistencies in the timing of the release of funds, and this haphazard notion of throwing one-off funds each year, as has just happened. Suddenly we have a release of funds and clients clambering to try to get equipment built in time.

Any change should, we suggest, be driven by an underpinning value that recognises that as a community we have collectively worked towards improving the quality of life and level of inclusion of people with disabilities. Consequently, we are experiencing longer life expectancy for people with disability who have complex needs and this commitment should be part of a mutual obligation; that is, by embracing the value to improve the quality of life for people with disabilities. It follows we have a mutual obligation to ensure the maintenance and support of their needs, particularly in the area of accessible equipment as it is essential for them to enjoy quality of life.

We believe we need a more robust methodology to costing the needs of people with disabilities, including a system to allocate funding across the State. This demands fundamental restructure of the governance arrangements and resource management. We therefore suggest we at least shadow the recommendations of the KPMG report into the review of the Tasmanian disability sector, which, I believe, is yet to be made public. It is about to be presented to the minister, although it has been presented to the disability sector in consultation. We are suggesting that we would either operate under a like governance and funding system proposed by that review, if it is indeed adopted, or one that is integrated into the governance and funding arrangements that is adopted following that report.

Overall funding should be assessed against population needs planning, both globally and regionally, and allocation should be governed by regional committee structures consisting of non-government organisation representatives, and perhaps government representatives, charged with the duty to ensure objective allocation of funds. Again, if that arrangement were adopted it would mirror the recommendations of the KPMG report into the disability sector.

We also strongly submit that funding for people with disabilities under the scheme needs to be quarantined, ensuring that people with disabilities are not competing for funds with other groupings.

Ms MERRY - It is interesting there in that in the spinal account, for example, there are funds quarantined for clients with spinal cord injuries, yet that model does not exist for any other client group, so your general group in the community with disabilities are competing for funds then with people being discharged from hospital. The spinal group receives an inadequate amount from what I hear on the Community Equipment Scheme Committee and there is still that competition for basic equipment.

Mr SERTORI - We have noted that significant funding injections are required and we have talked about some of the options being pursued nationally. We have tried to think of a more imaginative response within the State that might assist to provide the necessary funding. We were interested in the Premier's recent flirtation with the notion of a State lottery scheme. We thought there might be some merit in considering its application to fund such schemes as the Community Equipment Scheme in Tasmania. I noted this morning before I came in that in Western Australia the disability equipment grants for individuals, Independent Living Centre of WA, is funded by Lotterywest. I can refer you to its web site - www.ilc.com.au - where details are provided. Obviously there is some method of allocating funds from that lottery to equipment needs and perhaps something similar could be thought of for Tasmania.

Ms MERRY - The WA model is one to be admired in that they seem to do very well with being able to source equipment for people with disabilities. The Disability Services Commission is separate from Health, and there is the support of such a lottery system. It appears to be the place to live if you need equipment.

Mr SERTORI - At the moment there is not a system to try to measure forward need for equipment. We suggest that the population planning system will help us in that regard to assess and measure the level of equipment needed. In particular it will also assist in determining the level of funding required into each of the regions.

Before I came in today, I said to Catherine, in her capacity as manager of Allied Health at St Giles, 'How much extra funding would you need to meet the equipment needs of the clients presenting to St Giles at this moment and perhaps the broader regions of Launceston?' Her response was that perhaps $2 million to $3 million extra would resolve that problem. We are, therefore, not talking about a very significant amount of money to solve a vital problem.

Ms PUTT - Is that annually or just to catch up?

Ms MERRY - That was a very off-the-cuff response. On an annual basis, if you look at the northern region, with $6 000 being distributed amongst the entire region you just about need a stiff drink after trying to split that up. Even four times that amount of money per month would not cover all of the needs but would certainly go a lot further.

Mr WHITELEY - What would your response be to evidence that was given by the department? They made a written submission. I asked a specific question - page 18 of the report - about non-standard equipment items that are on the waiting list and the number of people. That said, 'We are suggesting through this report that $609 307 is the total dollar value of non-standard equipment items on a waiting list for the total State as of June 2007', and it represented 187 people on that list. What would your response be to that figure?

Mr SERTORI - Rubbish. They would not know. They do not have a rigorous methodology in place to measure it. I think you will get meaningful information from those making submissions. They are out there on the ground delivering the service and seeing the people present each day who have given up registering in the system because they see it as a waste of time. Families that I know of are mortgaged up to the hilt to support their children; they have mortgaged their house, taken out funding to adjust their vehicle and taken out funding to purchase equipment for their child. They are sick of waiting or do not want to go around the charity circuit and beg because they see that as undignified - and why should they? But they are mortgaged up to the hilt. They are not registered anywhere, but I will tell you where they are. They are at St Giles helping us do our fund-raising and are the first to put their hand up to help us raise funds for others. If we can achieve anything out of this inquiry then they are the salt-of-the-earth people that we want to try to help.

Mr WHITELEY - Point taken. On that question, which I think all of us would be aware of, this unmet need mystery is probably as scary as hell, to be honest, if we were to get to the bottom of it. How do we get to tabulate that unmet need, rather than shooting arrows in the dark? How can we gather information across the State from groups like yours that represent people who have given up on the official departmental waiting list? How do we get that information to find out that need so that we are not just pulling figures out of the air?

Ms MERRY - I will probably get shot down in flames but I do not think it is that difficult. I look at our region and I look at the representatives who sit on our Community Equipment Scheme from St Giles, Disability Services, LGH, spinal et cetera. To a degree we know fairly well who our clients are. We know fairly well how many clients there are with catastrophic-type disabilities that need a huge amount of funding to put them back into the community. To a degree with our complex clients we can predict how frequently their wheelchair needs replacing, how frequently they need a new pressure cushion, how frequently they might need a renewal of their pressure mattress - things that wear out, so replacement and renewal - so we have a bit of an idea of the throughput. For example, if I have cerebral palsy client who can drive their own power chair and they are out in the community all day, living a lifestyle not that different from us in terms of being busy and out there, their power chairs are probably going to need replacing about every two-and-a-half to three years, or maybe five if they are very conservative and careful with it. Their seating or cushioning might need replacing about every two-and-a-half to three years, so there is a pattern of usage that is predictable with a lot of our guys.

There are quite a few things that happen to people that are once-offs, those catastrophic events involving a gunshot wound or myelitis, but again we have a bit of a pattern of roughly how many of those occur per year. I am sure the hospitals could provide a better pattern of predictability.

Mr WHITELEY - But none of this is available in any one basket, is it?

Ms MERRY - Not at present, but it is possible.

Mr WHITELEY - So it is possible?

Ms MERRY - I think it is.

Mr SERTORI - The information is there. If you took this region, an organisation like St Giles, the main organisation dealing with children with disabilities, certainly at that level can collect meaningful data if someone can develop an appropriate system to collect it. Then we can make forward projections by using that data. A lot of the data is collected but there is some vacuum that it goes into - that I have never visited - and it just disappears into the black hole. Then when there is a crisis you are asked to provide the data again. So there is something missing in the system to properly analyse that data and work with it.

I just conclude that no-one wants to look at it because they are fearful of what it might mean.

CHAIR - Michael, you mentioned your region. Is that the 63 telephone district?

Mr SERTORI - For therapies within Allied Health it is, except that our seating clinic is operated statewide and we have other services that operate statewide. So when I refer to the region it is 63.

Mr WHITELEY - Taking on board the information you just gave, I am encouraged by that. I would have thought that the information was there; it is just a matter of someone collecting it. On that basis, would a community equipment scheme be better managed outside a government department? Would it be better to be entrusted to whatever structure we find, say a group that could actually take all the politics out of it and say, 'Let's get on top of this' and then be funded by government to do it? Would there be merit in that?

Mr SERTORI - My proposition was that you have regional management committees -

Mr WHITELEY - Under the Department of Health?

Mr SERTORI - No, independent of it but with guidelines. Members of the Department of Health should be there because they have expertise and knowledge, but consisting of appropriate people who have a sum of money that is allocated based on assessment of population. So that if 20 per cent of the population in the northern region have a disability and equipment needs, then that will be reflected in the money allocated to that region. That committee is then empowered to allocate the resource across the client group, based on an appropriate assessment model.

That is the heart of KPMG's recommendations and if it is adopted then that will be the methodology in place to fund disability generally.

Ms MERRY - And that will work particularly well if you have that separation of money required to get people out of hospital and get them home, versus money for people who have long-term disabilities, who live in the community and need to be supported so they stay living in their own homes in the community and who can be managed.

I note the model of Rocky Bay in WA, which is allocated money to distribute for children, because that again is a specialised area and they know the priorities within that. So again there is splitting up of the funds to manage them in different ways.

Mr SERTORI - And there are side models. I guess St Giles might have a vested interest here in running the seating clinic, but the direct allocation of funding is to that clinic and then it is just distribution through the service. We would save the administrative overhead, provided there were clear guidelines to us in the setting of priorities, but I guess that being an effective business service we have a vested interest in that model but anything to try to eliminate the layers and eliminate the additional cost that results from those layers is worth consideration.

Ms MERRY - I do have to say, though, at this point that the Community Equipment Scheme Committee I feel works very well in the north. The professionals that are on it know their clients. They can weigh up the tiny amount of money and hopefully distribute it the best way possible but -

CHAIR - The CES scheme again, is that region - 63, 64 or 62?

Ms MERRY - Yes, 63 - I cannot speak for the other regions and the way they operate.

Ms PUTT - It was about regions that I wanted to ask. This is a really dumb question but I think it is better to ask the really dumb questions to make sure that you have it right. You talked about inequities between the regions and that seems to be a theme in a lot of the submissions. I do not understand how this regional allocation works or what the basic inequity is. I do not know how much you can tell me about that but I just do not understand what is the inequity.

Ms MERRY - I don't know that I can tell you much about that either. I almost feel that information, for example, from the south is a little bit secretive and we are not allowed to know so there is again a sense of mystery around who gets what and why. I do not think I can enlighten you any further on that one either.

Ms PUTT - Okay.

Mr BEST - We did hear from the department that historically that is how they managed and so different scenarios eventuated. I am just saying I think that has evolved so that you do get things - for example, the CPAP machines that were covered in Hobart that were not covered up here in the north-west and things like that.

Ms PUTT - So it is sort of a by-product of history and what we are hearing is that there is not some way of gathering the data together and looking forward that allocates it that way as opposed to on some historical basis. Would that be a fair summary?

Ms MERRY - I remember reading that.

Mr SERTORI - I think the inequity can be demonstrated. I do not have the data in front of me but perhaps historically there is a greater predominance of fundraising in the north than there has been in the south and it may well be that governments stepped in to fill the gap in the south and as a consequence, some of that history has remained. But if you were to adopt a population-based model that I was talking about then you would eliminate that.

Ms PUTT - Regarding eligibility criteria, in your submission you talk about the fact that if people get their equipment some other way then they cannot get further assistance in relation to that equipment through the CES.

Ms MERRY - I can give you an example. We have a family who have two quite young, quite severely disabled children and there is their frustration at waiting in line. To their credit, they have been out with a group of other community people who have fundraised, and they have fundraised both of their children's wheelchairs. We are not talking of an off-the-shelf chair here, they are quite complex, so you are probably looking at about $3 000 to $4 000 per child for their chairs. Because those chairs are not owned by the Community Equipment Scheme, the Community Equipment Scheme will not pay for repairs and maintenance of those chairs, even though there has been no impost on the scheme by this family who have two children.

Mr WHITELEY - Isn't that extraordinary.

Ms MERRY - It simply reflects how tight it is with the money and whatever inequities you might look at, it all comes down to quite insufficient funds, and it is reflected constantly.

Ms PUTT - The last thing I wanted to ask about was the impact of the $800 000 - how far you see that going.

Ms MERRY - It needs to be spent and invoiced by a particular date, which all leads to decisions being made and people who, on that five-tier criteria, might be closer to a four or five actually being funded, although I do not think there are too many of them because the needs in the 1. 2 and 3 categories were so high on the wait list. But to spread that money over the year I think makes for better, more effective spending and better prioritisation. We won't ever say no to a big lump because we can do stuff for people.

Mr WHITELEY - Coincidentally, it is an amount very similar to the amount in the bottom right-hand corner of the table I referred to. My little bit of information is that probably it will be dedicated to that waiting list issue of the 187 on the list and have been patient enough to sit on it, and the 6 009 that it actually represents, and a little bit more. It will be interesting to see how that all works out and how it reflects in their waiting list.

Mr SERTORI - A seating clinic without government funding is an extraordinarily difficult thing to run. For nine months of the year, we run at enormous cash loss and rely on fundraising to prop it up. Then, in the last few months, funds suddenly come in and you start to work towards breaking even, and you have the board scratching its head all year wondering where this -

Ms PUTT - It is really hard, yes.

Ms MERRY - Yes, because operating that service is dependent on what is happening out in the funding world and it is not a straight path.

Mr SERTORI - It takes at least 12 months, if not two years, to train a technician and when you have problems trying to predict your bottom line, you tend not to take the risk of putting people on to plan for the future. So there is a whole flow-on of things from the strange way of releasing funds, apart from just affecting the client group.

I am conscious of the time. There are two other things I wanted to ask the committee to give consideration to, as you are conducting this review. The first is the conduct of a costed service benefit analysis that would assist to measure the longer-term benefit of funding particular needs. By that I am talking about perhaps funding home and vehicle modifications for a client who would otherwise end up in institutional care. So you have a cost of doing that against the longer-term benefit and it is something we tend not to talk about when we look at the scheme. Funds invested in the scheme could well be a critical investment in terms of saving the community funds in the long run but improving the quality of life of the individuals.

The other is that we should not look at the specific benefit of providing equipment based just on the circumstance of the individual with the disability. We need to look at it a bit more broadly, at the circumstances that surround that client - indeed, their environment or the context in which the equipment is used. In many cases the equipment may be required to provide an improved OH&S benefit for the people who are supporting that client.

Ms MERRY - At the moment that is not permitted under the Community Equipment Scheme. An example is a client who was a St Giles client and now is an adult. So that client is quite tall in a wheelchair, being pushed around by support workers of varying stature and in order to have that client able to be out and about in the community, the idea was to go to a power chair with an attendant controller so that the support worker can drive the person around instead of pushing. We do not have flat terrain here, do we? That is an OH&S issue for that shared home where that client lives so it is not regarded as being eligible under the scheme.

So the total environment really does need to be considered.

Mr SERTORI - Finally, we would like to see any changes to the scheme subject to some sort of performance indicators so that we have an ability in future to measure the performance of the scheme, particularly the effective impact of any funding or additional funding that is applied into the scheme.

At the moment there is not a system of measure.

Mr WHITELEY - But even if we attempted to at the moment it would not be a fair representation of an indicator because we would not be measuring against the needs. We are only measuring it against a portion of the noted need. Would that be a fair comment?

Mr SERTORI - Yes, I agree.

Mr WHITELEY - On that point, before I lose the thought, you talked about Western Australia and other models across the world. I have a very practical question, Mike. Is anyone anywhere practising this future planning stuff? From a business background, it really worries me that there is no tracking. Is there software available or programming available within the sector that enables the database to be established with Joe Bloggs and everybody else on it and then a future planning model that gives us the opportunity to be able to see five to 10 years out where this need is going? I know in point E, you talk about strategies to ensure forward planning. Not everything is predicted but a lot is. You know that someone is going to reach puberty and we have dealt with people in our own electorate, probably both the same people. When a young boy in a wheelchair goes from primary school into high school everybody knows that at some point in that 18-month period there is going to be a need for a new wheelchair. It is not hard to work it out and that wheelchair will probably cost *x*. I do not think anybody is doing any of that work. We do not have a clue from one day to the next what is going to happen in five years' time in this State, given we are overrepresented in the statistics anyway.

Are there programs available? Is it possible for that work to be done? Finally, is that the basic work that has to be done for us to really get a handle on this?

Mr SERTORI - Most companies can forecast and the modelling has been there for years. The Australian Bureau of Statistics is a good example of an organisation that can forecast and I would have thought Treasury, with its modelling, can forecast. We just do not bother to do that in disability.

Mr WHITELEY - Because we are scared?

Mr SERTORI - It has been a low-priority area in this State.

Ms MERRY - You interface that with perhaps some clinical knowledge of what to expect.

Mr WHITELEY - But am I simplifying this issue of reasonable predictability of a client?

Ms MERRY - No.

Ms PUTT - Surely there must be jurisdictions that do predict?

Ms MERRY - If you look at a client who might have some legal case, their future needs have to be predicted right out for their entire lifetime. So it has been done.

Mr SERTORI - Indeed, with the national insurance scheme that is being put together, there must be actuaries at the moment working on those very forecasts so that the models are indeed there and we need to be brave enough to adopt them in this State and at least measure the extent of need, as we talked about earlier.

Mr WHITELEY - In the absence of a national strategy, which may very well represent one of our recommendations at the end and we should continue to give support to that, this committee is going to have responsibility to put together recommendations for the known model we have which is a State- delivered service. So we have to have both.

Mr BEST - In the national scene, what is the cohesiveness across States? You are obviously St Giles. Are there other groups? Are you a member of an association that advocates nationally?

Mr SERTORI - We have our affiliation through National Disability Services, which represents about 500 disability organisations. Ability First Australia is six organisations looking after 40 000 people with disabilities. Through those bodies there are now networks being formed to in fact provide a united front to pursue the very issue we are talking about.

Mr BEST - Is there a document that this committee could have about those national issues where you have all agreed about some of these things that you mentioned - an insurance scheme, tax, for example, or Medicare?

Mr SERTORI - If I could defer that to Professor Reynolds because much of that information would be released under their letterhead. Margaret is to appear before you, I believe, if she has not already done so.

Mr BEST - Okay. On the island model, they cover all of the equipment, is that right, and they have some tax deduction for people?

Mr SERTORI - I am not sure about the tax deduction.

Mr BEST - Okay.

Mr SERTORI - I did a study tour there a few years ago and my understanding is that they cover them. They cover all forms of equipment for people with disability up to prescribed levels, a little similar to our Australian Medicare scheme - a claim form.

Mr BEST - Would you have a report that you could share with us?

Mr SERTORI - Not at this moment.

Mr BEST - That is okay. On the level of funding inadequate, you say ours is the lowest level per capita. Do we have any figures as to why we are the lowest?

Mr SERTORI - Why we are the lowest?

Mr BEST - Yes. What do they spend in New South Wales or Victoria?

Mr SERTORI - It is in our submission.

Ms MERRY - New South Wales is $273 per capita -

Mr BEST - That gets back to where you say there is a feeling that it is not on the radar in a sense - and that answered the previous question about forecasting - for some reason it is not seen as an important issue.

Mr SERTORI - The equipment?

Mr BEST - Or the amount of per capita funding at this point in time is something that has not been seen as important and we have dropped right away in comparison also to the expansion of people's requirements -

Mr SERTORI - I think we have had a belief we have been putting additional funds without realising that the pool of users has grown substantially so people with disabilities have fallen well behind.

Ms PUTT - It has looked like more money but it has not recognised the demographic trend.

Mr WHITELEY - We have the highest rate, as I understand it, of people with disabilities anywhere in the country.

Mr SERTORI - One in four people in Tasmania have some form -

Mr WHITELEY - And one in five that have a reasonable limitation - is that about right - about 18 per cent?

Ms MERRY - I am not quite sure.

Mr SERTORI - I would want it rechecked but I think that is right.

Mr BEST - That fits then with this idea of a better measurement system. There was an example that you gave about somebody who had a stroke - $2 000 for a mattress, $2 500 for a bed that lifts and that sort of thing - do you see then that the funding can be sustainable? You mentioned a figure - and I know it is a rubbery figure; you said something like $2 million or $3 million worth. I know it was just an indicative sort of thing and I don't want to sound harsh, but do you think that it is going to be possible to provide for people.

Ms MERRY - Well, how long is a piece of string? But you still have criteria and priorities.

Mr SERTORI - We are committed in this State to try to provide better quality and support for people with disabilities, recognising their rightful place to fully participate to the level of choice in the community. We got rid of the institutions for that reason. That is the mutual obligation they talked about and you cannot half do it. You cannot say on the one hand that we will get rid of the institutions and we will let people participate in the community but we will not support them. It is not either/or.

Mr BEST - No, and it gets back to that point that you make about the way that instead of just looking at the benefit within the context of improving an individual condition there needs to be consideration of the circumstances surrounding the environment, OH&S and that sort of thing.

Mr SERTORI - Adding specialised brakes to a manual wheelchair can have a huge impact on that family -

Mr WHITELEY - Especially down a hill.

Mr SERTORI - Yes. It might cost $1 000 to install but the benefit could be quite considerable.

Ms MERRY - It is almost a joke trying to compare the cost of equipment to maintain people in their own home versus the cost of providing a hospital bed while they wait for a nursing home bed. The former is such a small amount compared to what the demands on the system might be otherwise.

Mr WHITELEY - Or equally then finding themselves in hospital with bed sores.

Ms MERRY - Yes.

Mrs BUTLER - I would just like to congratulate you on the quality of your submission. I thought it was terrific. I have a social work background and I have been to St Giles in the past. Would you just quickly say whether you could set up something really terrific with repair and maintenance? That seems to me to be an area that would not be too hard to fix; it is a huge gap.

Ms MERRY - We have made recommendations of that sort. For example, with our work with MAIB there is the question of power chairs. It is like having a car; you need to do regular maintenance to keep yourself up and running. Then there is the point that people who have highly-customised seating - their bodies are still changing or ageing, all of those factors - need to have a regular seating review to prevent there being pressure issues or other postural issues and pain. It is a little individual, depending on people's usage and lifestyle, but all of that should be provided. So we make recommendations through our seating clinic for those sorts of reviews for both mechanical and the body-type reviews.

Mrs BUTLER - And a lot of that could be done in Tasmania?

Mr SERTORI - My word. Regrettably there are a lot of experts that are not trained, so they tinker and cause all sorts of problems by making adjustments they probably should not and in the current regime that is probably encouraged. It could also be an issue of safety.

CHAIR - We should now conclude folks. We have gone over time because it has been very interesting. We will have a final point.

Mr BEST - I think it was excellent submission too.

Mr SERTORI - Thank you.

Mr BEST - I think you are right over the issues and I really appreciate the comments. You did clarify that you are providing these services; you have a business interest, I suppose. Your main focus is on supporting people with disabilities in the community. Would you clarify how you balance that fact that you have to run a business to provide the services and whilst you might have a key interest in all these things, from a business point of view, your main focus is really about your services?

Ms MERRY - The seating clinic is separate from our health services.

Mr WHITELEY - Any money you make goes back into the main -

Mr SERTORI - That is right.

Ms MERRY - Yes, we try to break even.

Mr BEST - How do you see the role for government to work with you?

Mr SERTORI - Give us a dollar and we will turn it into $2.50 - a working partnership.

Mr BEST - But that is not happening, is it?

Mr SERTORI - No, it is not.

Ms MERRY - But it is interesting that having just recently done a study tour around Australia with our AFA colleagues, I found that very few seating clinics appear to be funded by government. They are all struggling along in the same fashion. If that is a precedent, I do not think it is a particularly good one in the services being provided. Again, it is a small group who do not have a big voice.

Mr SERTORI - We are not seeking government funding to run our seating clinic, we are more than happy for the client group to be funded and then make the choice as to who they go to. If we are performing they will come to our seating clinic. For St Giles money is second, client first. We look after nearly 3 000 people over a year and we raise more than $1.5 million thanks to the generosity of the people of Tasmania and whilst the need presents, we will meet that need. It is important to stress that I use the word 'business' in the loosest sense - we are a not-for-profit charity.

Mr BEST - I understand.

Ms MERRY - The other thing I want to touch on is the impact on suppliers. There is a very small number of medical equipment suppliers in Tasmania and I know that in recent times some of those have been putting off staff. If we lose those suppliers and those agencies in Tasmania, we are dealing across Bass Strait in order to get equipment. To get equipment to trial with people, to get our back-up in service, it is a huge issue, so the lack of equipment funding has impacted on our suppliers as well.

Mr WHITELEY - And in turn makes it more attractive to get them in.

Ms MERRY - Absolutely.

CHAIR - Thank you very much Catherine and Michael. Unfortunately we only allocated you half an hour and I think we could have given you a couple of days.

Mr WHITELEY - It would be fair to say that if there is anything they think we still need to understand a little more, they can send us some further correspondence.

Mr SERTORI - I extend an invitation to each and every one of you to visit - I know Kerry has been there - so we can show you the seating clinic and how it operates.

CHAIR - It may be that we could decide to do that. Thanks very much Michael and Catherine.

THE WITNESSES WITHDREW.

<u>**Ms KAREN FROST**</u>, EXECUTIVE OFFICER, <u>**Mr CHRISTOPHER BRYG**</u>, OCCUPATIONAL THERAPIST AND <u>**Ms PHILLIPA O'CONNOR**</u>, OCCUPATIONAL THERAPIST/INFORMATION MANAGER, INDEPENDENT LIVING CENTRE (TAS) INC, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR - Thanks very much everyone and welcome to our inquiry today.

Ms FROST - First of all, I want to thank you for inviting us along to this and we are very pleased to be here today. Independent Living Centre (Tasmania) generally is an information service, non-profit, charitable organisation that has been around since 1993 in Tasmania. There is one Independent Living Centre in each State and we all collaborate on a national level. We are loosely affiliated. Also, as a group, we operate with a memorandum of understanding between each other. We are also a member of an international body of which Abledata in the United States is currently the chair. We also have a lot of local affiliation and memberships of other groups around the State.

Primarily we provide information about equipment for people with disabilities and for older people, not just equipment but also assistive technology.

CHAIR - How do people come to you?

Ms FROST - They come into our centre. They are referred by other people, services, organisations, Commonwealth Carelink centres or things like that.

CHAIR - Hospitals?

Ms FROST - Hospital, doctors and other allied health care, any service workers and anybody who hears about us. We have Internet, e-mail, telephone, fax and a web site. We travel all around the State to talk to groups and then we have follow-up conversations with individuals from those groups who want a more in-depth consultation. We have occupational therapists who provide information to the people so they have an understanding about issues in the future with the condition the person has. So it is not just talking about what you can do now; it is also about what will happen in the future. Will this piece of equipment help? Yes, but in six months you might need this or in three years you might need to look at that, or your condition may require that in the next couple of months you may require eating aids, or does the person have trouble swallowing or walking or other things.

As an information service we talk not just about equipment but also about alternative ways of doing things. Maybe there is something that they have already in their own home that they can adapt so it is not just about buying things.

We also provide unbiased information. We have a centre in Canning Street and have more than 1 200 products on display there from a variety of suppliers, and two or three of the same thing from different suppliers. We get what the people give us and our suppliers are very supportive of us for that reason. We provide information to people about what is appropriate to them and where they can get it. A piece of equipment might only be available through one supplier or maybe they cannot get it in Tasmania. We have a list Australia-wide.

With our affiliation with other independent living centres we have a national database and we have a local database. Our local database has more than 5 000 products and nationally we have around about 8 000 products as a combined group, so it is pretty intensive. A huge amount of information is there, and growing all the time. The information is written from an occupational therapist perspective, so the dimensions and information are correct and everything is verified before it goes onto our system.

Mr WHITELEY - You were here to hear some of the questioning in relation to forward planning -

Ms FROST - We do that, yes.

Mr WHITELEY - You track them; you have systems and databases in place that are predicting some of this stuff?

Ms FROST - Our database at the moment does not but we do have access to one that will.

Mr WHITELEY - That is a client-by-client basis?

Ms FROST - Yes. ILC (WA) runs the Lotterywest communication system and we can certainly use their system.

Mr WHITELEY - That is what we were talking about before.

Ms FROST - Yes.

Mr WHITELEY - So it is there; it is only a matter of plugging the data in. Is that a fair comment?

Ms FROST - That is absolutely right. The definition of 'assistive technology' is 'any device, system or design, whether acquired commercially or off-the-shelf, modified or customised, that allows the individual to perform a task that they would otherwise be unable to do or which increases the ease and safety with which a task can be performed'. Under that definition, which is very broad, a pen or a car can be an assistive technology device -

Laughter.

Ms FROST - but of course we narrow it to apply to people with disabilities or people who are ageing.

Mr WHITELEY - We take so much for granted as able-bodied people but the simplest little device can make an awful lot of difference to someone's day.

Ms FROST - For example, apart from these chairs in here, how many of you sit in ergonomic chairs? That is an assistive device and we actually have quite a number in our display room. An ergonomic chair is an assistive device that most people use every day. There are a lot of things. I have only been with the organisation just over 12 months and when I first walked in I said, 'I've got one of those and one of those'. I have glasses and they are an assistive technology device but they do not come under the community equipment schemes.

Mr WHITELEY - Maybe we could add that on.

Laughter.

Ms FROST - We applaud the review and think it is very good to see that Tasmania is doing this, and not being the last State as is often perceived to be the case. We are aware that New South Wales and Victoria have done similar reviews in the last few years. There was a major review in the UK recently and that is in the process of being assessed - the Transforming of Community Equipment and Wheelchair Services program.

Ms O'CONNOR - And there was one in 2 000 about the provision of equipment to old and disabled people by the NHS and social services.

Ms FROST - Yes, and this one was 2006. I have articles from the *Examiner* since June last year about the equipment scheme or funding for equipment in Tasmania. On the bottom I have written the link to the UK review

The overriding principle is that any improvement or change must centre on the interests of the individual. They are saying that the new system will not change the assessment process but it will change the provision, with accredited retailers exchanging equipment for a prescription, so that is a different approach again. We have not mentioned that in ours - I only found that recently. Self-funded people will be able to use the same system but will be charged a fee. They will buy their own equipment but be charged for installation, training, maintenance and things like that. So if a central system is set up that does all of the installation, training and maintenance then anybody can use it and people who can afford to will pay for it. So that is another alternative.

CHAIR - That is the UK model?

Ms FROST *- Yes. Tasmania Together - as reviewed in 2006 - has overarching goals as being a reasonable lifestyle and standard of living for all Tasmanians. The cost of living is the headline indicator but how can you achieve that if you do not have reasonable access to equipment or communication? One goal is 'confident, friendly and safe communities', but if there is inadequate provision of equipment then communities or individuals do not feel safe. 'Active, healthy Tasmanians with access to quality and affordable health care services' - speaks for itself. 'Vibrant, inclusive and growing communities where people feel valued and connected' but how can they feel valued and connected if they cannot communicate, get out and see people. Equipment is not just about wheelchairs; it is about augmented, alternative communication and environmental control devises.*

We used to produce a magazine, but no longer have the resources to do so, and this is an extract from 2004. It has good information about communication and environment control devices.

CHAIR - That was my question.

Ms PUTT - Automatically opening your door and things like that?

Mr FROST - Yes, the picture says it all. You can use it with your cheek; you can blow into a straw; you can use a finger and you can do all of that stuff in your own home. It is really important for that not to be left off. At the moment it has such a low priority that unless it is deemed to be a major need for somebody it usually does not get funded. It is not that the Community Equipment Scheme has the funding priorities all wrong; it is just that there are not enough resources.

Mr WHITELEY - You have to have a priority list if you do not have enough resources.

Ms FROST - That is right - and every single thing cannot and maybe should not be funded. I am not the one to say what should and shouldn't be funded.

Mr WHITELEY - At what point does that list become an open list of provision of equipment and assistive technology? At what point do we stop feeling as though the community, through its fund, has to provide? My gut feeling is that we should provide everything that is deemed to be appropriate, but at what point would the person have to take responsibility up to a certain level of funding?

Ms O'CONNOR - I would probably pose another question: at what point does a doctor say, 'I am going to prescribe this medication to help you with your cold'?

Mr WHITELEY - Good point.

Ms O'CONNOR - You are not going to die from that cold and it is not going to influence you a lot - that sort of idea. What are the cost benefits? We are not saying that everyone who may need an environmental control should get an environmental control. There is a difference with someone getting an environmental control but they hardly use it. On the other hand, someone who needs a communication device - which in some cases can double with some sort of environmental control, that by providing that equipment you are enabling them to work, to socially function, to get out and about. So it is to some degree countered by what sort of benefits you get out of it but there is a certain standard of living that you try to achieve.

Mr WHITELEY - You understand why I am asking the question?

Ms O'CONNOR - Yes.

Mr WHITELEY - The Pandora box opened when you started talking about assistive technology. You pulled off your glasses and I am going, 'Whoa', and I didn't hear you asking for your glasses to be funded.

Laughter.

Mr BRYG - I guess your glasses might be partially funded by Medicare through that system so really it is an assistive technology device that is funded through the Government.

Mr WHITELEY - It is now - or through private health cover, that is right.

Mr BRYG - I do not mean to push that example but I think that in looking at assistive technology we have to ask what is the point. The point is to enable someone to be more independent, to perform activities more independently or more safely, and the underlying principle behind that is that people are valued to contribute to the community, that everyone should have equal access to the same things to be able to do the same types of activities. So we are talking about function, we are talking about people functioning within the community and contributing to the community, but also the health benefits that they receive from that. On one hand, if someone has the right equipment for their needs to be able to function within their community, then they can contribute to that community. On the other hand, if I am able to do things then consider that with my mental wellbeing, consider that with the education that I might be able to access, consider that with the other health benefits that are provided to the individual, so it goes both ways.

To summarise and answer your question, I think you should look at the functional benefit to the individual. One might think that there is a Pandora's box to be opened and that a long list could eventuate.

Mr WHITELEY - The view of St Giles is that the official waiting list is not representative at all of what is out there.

Mr BRYG - I would agree with that.

Mr WHITELEY - My personal view is that in an ideal world we should be able to fulfil all of that.

Ms PUTT - But we also would have a system of prioritisation if we had enough money.

Mr WHITELEY - That is where I am getting at, how long does that list become?

Mr FROST - The other part of that is that with appropriate assessment by occupational therapists and other qualified -

Mr WHITELEY - They are not always the ones doing the assessment though.

Ms FROST - They are not, but by appropriate assessment those sorts of issues are covered because an occupational therapist will say you will get more benefit by putting the money into this, than that, and we will put them on a different priority system within each category even. So within the priority system you still have priorities.

Mr WHITELEY - Thanks for that.

Ms PUTT - So that having enough occupational therapists then becomes one of the issues?

Ms FROST - It is a huge issue.

The Disability Framework for Action 2005-10 talks about accessibility and equity, and all that stuff they talk about is excellent, the right to live free of discrimination, but the

CES inadvertently discriminates due to a lack of funding. Accessibility at what cost and who pays? And equity, how can people have equity if they cannot communicate? So there is the Disability Framework for Action and *Tasmania Together* - they are there but they are being undermined by not funding things or helping people to access and to do the things that they are saying we are going to do. The Disability Framework says:

> 'A society that highly values our lives and continually enhances our full participation'.

So they are saying on one hand that they are committed to that and yet in the north, the Community Equipment Scheme has been cut by $6 000 this year.

Mr WHITELEY - Back to $69 000.

Ms FROST - It is $69 000 for the year, so it is less than $6 000 per month. As you heard Catherine say, there are so many people and such a high need. I give the panel full marks for how they make those decisions. I would hate to be in that position, it must be very awful for them to know that there are a number of people who are not going to get funded for some time, even though they have high needs, and some who will never get funded under the current funding arrangements that the CES has.

CHAIR - Can I ask something, Karen, in respect of the people that you deal with who come into the Independent Living Centre with their needs, their wish list and their requirements and seeing what is available to them. How do you find that the circumstance of the financial support for them limits them in what they are able to achieve? When they say, 'I think that suits me' and it has a price tag of *x* number of dollars, what is their reaction to probably not being able to achieve that because of the lack of funding?

Ms FROST - The first thing they say is, 'Where can we get this second-hand?' and they often settle for a less ideal piece of equipment or they will go and talk to their families or our staff will talk to them about the various schemes that may be available for them to try, and good luck to them with that. But certainly, yes, it is very hard. We do not follow up with people once they leave our premises. What they do with the information we give them is entirely up to them. So we do not have a lot of feedback from people but we have had feedback from some. We had one recently who rang up and after 14 months or so finally had some joy with -

Ms O'CONNOR - She had finally received the funding. Part of that was because obtaining assessment took time, trialling took time, various options took time and then she applied for funding and I received some feedback about that because I had initially started off that process and said, 'These are you options, approach the occupational therapist at the Launceston General Hospital'. I used to work there and that is why I know the system fairly well. I said, 'Approach these people and then go through the process. It is a very slim possibility but it is worthwhile pursuing', because she was very active and it would have be a huge benefit in her life - and she ended up getting funding, which was fantastic. Having said that, one of the biggest things that we have had just recently is a situation where people have received funding for one thing - for example, they have funding for a wheelchair or they already own a scooter, not funded by the Community Equipment Scheme - and they ring us and they say, 'I have this device, it is fantastic, but

I cannot get it in the car'. I said, 'That is all right. How big is it?' 'It is a scooter'. Usually they need an electric hoist to get it in the car. They are not funded. So even though they might fund the wheelchair, fantastic, brilliant and wonderful, they cannot do anything but maxi taxis. So if you have someone maybe in outer Devonport, outer Launceston, Evandale or in the Longford area, they are only allowed to go down the street; they cannot get anywhere. They cannot go on a family holiday. They might have some community transport but it is still quite restrictive. So it has come so far, but they are not independent.

I have had examples of people either going to work or university who have a manual wheelchair, but they cannot get the wheelchair into and out of the car themselves. So they can drive and they can get to the place but they cannot get out of the car.

CHAIR - Is it an expensive process to provide that hoist into the car?

Ms O'CONNOR - It varies. Sometimes if it is a manual wheelchair it is a matter of a couple of hundred dollars and most people are fairly happy to pay for that, and that is just like a bike rack. But a hoist to get it into the boot, if it is a scooter or an electric wheelchair, costs about $1 500. In some circumstances people who can drive may be able to still use that hoist and walk the short distance from the boot to the car door but in some circumstances they cannot and it is a case of looking at a hoist that takes a manual wheelchair up or a manual wheelchair and an electric wheelchair, which is not necessarily allowed in the CES. They say, 'An electric wheelchair. You do not need a manual' and then that might restrict them when they might be able to use a manual for short distances or if they go out and about.

It does vary a lot. There are a lot of solutions to the one problem and one of my main jobs is often trying to figure out the most cost-effective way for that person to do it, and there is often a lot of compromises and a lot of situations where they say, 'I cannot afford that' and they are just stuck. They might be out on a farm, have the scooter and cannot get into to town.

Ms FROST - You asked about cost-effectiveness. There is the international classification of disability, I cannot remember the full name of it, the ICF document that Australia adopted in 2004 which has been rarely used to classify and to work out disabilities. Independent Living Centres Australia have commissioned some research to work out some scenarios using that document to try to work out cost-effectiveness of different items of equipment in different circumstance because it is not just, 'I can give you a set of crutches and you a set of crutches for short-term use', they will have totally different cost implications. You might have steps and you might not; you might work and you might not - different things. So the cost of giving the crutches might mean that you can get back to work whereas you do not leave the home and you are stuck in front of the TV and you do not want to do anything else or you cannot communicate with anybody else.

Mr WHITELEY - They are very individual needs.

Ms FROST - Yes, and that is one of the difficulties about working out how cost effective it is, so this research that we are conducting will take about three years to get through. There is also a spreadsheet that an Italian organisation - I have the information back at work - the Don Giovanni Foundation, has developed. I have seen the costings for a stair lift versus an elevator versus two carers and the idea was that one person needed to get out of the house twice a day to go to the shops or something but just had trouble getting down the stairs. They costed this over a 10-year period, with no indexation, just based on current costs. To put in a stair lift, the stair lift would need to be replaced after five years, there would be the maintenance on the elevator, carers twice a day for whatever time, and over 10 years the cost of the carers was estimated at something like $87 000; the elevator, $15 000; and the stair lift, $18 000. So it is not the one-off cost which seems really high but it is the ongoing cost and the implication, and with the carers you have not just got wages but you have then issues with occupational health and safety and the problems with lifting and transferring and everything else that we all know about as well.

This is a very basic spreadsheet that is available now and it is admitted to be very basic; it does not cover all the other implications. I can send that information to Charles. There is a lot in Italian but there is an English version.

Mr WHITELEY - That would be helpful.

Laughter.

Ms FROST - He came out last year and presented it to us and told us how it all worked, and that was very interesting.

Also Community-based Support in Hobart are working currently with the university to work out how much they are saving. They are running a pilot scheme with HACC about providing equipment to people in their homes - basic equipment like the bath chairs - some basic home maintenance and personal equipment, hygiene information, eating information and things like that, just some basic things, and they are finding already - and they have only been doing it for about three or four months - that they are saving a lot of money in wages. By helping people to have an appropriate showerhead and a seat in their shower they are not having to have somebody go in and shower people. They are already finding that information and they are using the university to help them to work out the data on that so that they can use that as a research tool.

Ms O'CONNOR - Community-based Support are putting in bidets, and they can be retrofitted quite easily - I think it is $200 to put them into a client's home. They are finding that clients who had carers going in to toilet them on a frequent basis are no longer needing that input or are needing less input. It is also a matter of dignity and all those sorts of things, as you can imagine. I cannot give you the exact details but it would probably be around $3 000 for that bidet but that has reduced the number of visits. They are finding that they are absolutely fantastic.

Mr WHITELEY - If you had a magic wand, which would be lovely, what two or three practical recommendations would you make - there are probably 102 things - that would make a significant difference to the way in which the current scheme operates?

Ms FROST - Firstly, I would lobby the university to include occupational therapy as a subject in Tasmania and get more occupational therapists in Tasmania. Somehow we need to raise the funding for occupational therapists to attract them to this State. We need occupational therapists in Tasmania to do the assessment because often the backlog happens because people are waiting for an assessment. Services such as Fusion and places that do home modifications are up-to-date. They have no big waiting lists.

Mr WHITELEY - Because they haven't been assessed?

Ms FROST - Because there are people waiting to be assessed. So there are some inequities in your figures there.

The second one is to put some reasonable funding in - you don't know how much; how long is a piece of string is how much funding we need. We have no idea because the numbers are doubled up in different places because people are on two, three or four different waiting lists for different groups around the place; people are not on waiting lists at all or whatever. So put in something initially but review it and review it regularly. Review it not just with CPI but look at getting decent waiting lists. People do not go on waiting lists because they think what is the point, but once word of mouth gets around that, 'Hey, there's a chance here', then people will go onto the waiting lists and they will become more involved in it.

Mr WHITELEY - That is when you have to hang on to your hat.

Ms FROST - Exactly. Then put in a plan for future funding or other ways of maybe working out the priorities and the funding and things like that. But basically get some money up there, get it to a level where you can at least be helping people - at the moment I think in some places it almost is a joke - and review it properly. It does not have to be annually but it certainly has to be regular. It might be six-monthly to start with but it needs to be not just CPI, it needs to be actual incremental increases that are realistic.

The population is going to age, there are increasing numbers of people in the disabled area. As Mike said, we have statistics on that from the ABS and we know how old people are going to be, we know the tables, we know when it is going to happen. We know that it is going to increase exponentially.

Ms O'CONNOR - And that includes increasing caps because caps present a huge problem.

Ms FROST - That is what Mike said as well, the indexation. The equipment has gone up massively in price and yet the caps have pretty well stayed the same.

Ms O'CONNOR - So increasing caps but also allowing some flexibility. For example, a $2 000 cap on an alternative communication device is definitely not adequate for a lot of electronic versions. Also, you might have an alternative communication device but it may also be able to access the computer environmental control so it needs to have some flexibility even above that cap. So if you have a client who is sitting there and you could achieve so much if you could get -

Mr WHITELEY - An extra $2 000.

Ms O'CONNOR - Yes, just a little more on top of that communication device would enable a huge door to open.

Mr BRYG - So what you are saying, if you do not mind my supporting your statement, is that perhaps the committee assessing the applications need to have some power or flexibility to make that judgment because they have that professional background and they have the submissions before them. Perhaps they can make a decision based on that application and have some discretion with that.

Ms FROST - A couple of issues. If someone is discharged from Launceston or Hobart hospitals but they are not in that region, which fund does that come out of when you have it regionalised?

Mr WHITELEY - Is there a confusion?

Ms FROST - There can be. Also there is the issue of who owns the equipment. CES puts in $6 000 towards a $20 000 wheelchair - when you sell it or move on, does it go back to the CES? Who maintains it? Who owns it?

Mr WHITELEY - Very good question.

Ms O'CONNOR - If the client has put in 50 per cent of the cost of the wheelchair, should they not be able to try to recoup some of their funds? By the same token, if CES owns it, that is a wheelchair that probably has gone into a secondhand market that may not be appropriate for the next person who gets it. They deplete their funds and they are not eligible for maintenance if the client owns it.

Mr WHITELEY - Do you think there is much useful equipment sitting in people's attics and garages?

Ms FROST - Yes, there was before it all got rusty and not maintained.

Mr WHITELEY - Do you reckon there is a lot of stuff out there? Jo Blow has died and his wife or his partner is left with this stuff.

Ms FROST - ILCA estimated in 2006 that a third of equipment is abandoned.

Mr WHITELEY - So some of it would be of use?

Ms FROST - Oh, yes.

Ms PUTT - It was an issue in either your submission or in the previous people's submission about equipment the department had in Hobart that was known of up here. Eventually they had to go and find it, drag it out of the storeroom and use it, but the department did not know they had it.

Mr WHITELEY - I wonder if we are at a point where we could engage the TV stations, in a community service way, to bring the stuff back home.

CHAIR - That could be a recommendation, thanks very much. Thanks very much, Karen, Phillipa and Chris, for your submission today and, again, that invitation is there. Obviously we are stimulating a lot of thoughts and we can hear that you probably have a lot more to say. Perhaps if you wanted to present again to us, in a written form, any extra information please feel free to do that. Anyway, thanks for your time today, we appreciate it.

<u>THE WITNESSES WITHDREW</u>.

<u>**Ms JANE WARDLAW**</u> WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR - Jane, we thank you very much for your time in coming to present today. It is really helpful for us to talk to somebody who needs assistive technology and to understand the issues that you obviously have had through your life. So we will hand over to you to make your submission and then we will ask questions.

Ms WARDLAW - Yes, thank you. If you do not mind for the purposes of this particular hearing, rather than using the words 'people with disabilities' I would prefer to use the terminology of 'people with differing abilities' and also if you do not mind I would like to read from my submission.

CHAIR - No, that is quite okay.

Ms WARDLAW - I do not usually do this but there is quite a lot that I would to say that I have been thinking about for some time, and I will try to articulate it in this document, a copy of which I will leave with you.

The following submission to the committee aims to highlight some significant considerations facing people with differing abilities. These are: that they have the fundamental right to life choices and opportunities as much as able-bodied people; that it is a government duty and responsibility to ensure tools are provided to encourage self-determination and responsibility for life choices; that the provision of assistive technology and equipment is viewed as the provision of fundamental tools for quality of life and life expectancy; and that the provision of such tools alleviates economic expenditure pressures in other areas of the public purse, such as personal care support, institutionalised care, chronic illness, hospital stays and welfare dependency. A more transparent and accountable process must be facilitated by government. There appears to be a culture that prevails in government that people with differing abilities are not worthy members of society and should be grateful for the investment made into the sector. The disability sector itself actually contributes to the economy through employment, small business, manufacturing and innovation technologies.

Finally, this submission advocates for a public stand that the Government will continue to fund more generously the provision of assistive technology and equipment to people with differing abilities. I would just like to expand on a few points here.

Providing assistive technology and equipment for people with differing abilities is essential to ensure independence, quality of life and recognising that people of different abilities are valued members of society. Such people play an essential role in our society in that we can contribute to the economic and social wellbeing of humanity and the Australian way of life if provided with the essential equipment and aids, mobility and communication. It is vital for this inquiry to understand that generally people with differing abilities wish to be independent and have the ability to live functionally and independently in our society to pursue dreams, goals and ambitions. Importantly, assistive technology and equipment is a tool for breaking the poverty and dependency cycle, thereby providing the tools to support self-determination and responsibility.

The prevailing ideology must be that it is government's role to provide tools to assist with self-determination and responsibility for life choices and participation. Governments provide resources to build and nurture human, natural, social and productive capital to engage and enhance broader community economic development. Most governments provide communities with the tools to adapt to change and develop their communities to participate in development and sustainability - economically, socially and environmentally. The same principle must apply for people with differing abilities. Providing the essential tools gives individuals and their families the capacity to be self-determining and responsible for their futures.

Fundamental requirements, such as quality personal care, quality assistive technology and equipment including transport, provide the individual with the freedom to pursue the same life options as able-bodied people and it is a worthwhile investment. The lack of the provision will impact severely - economically and socially. Without assistive technology and equipment for those with differing abilities, the capacity to function independently is severely limited. Barriers - social, emotional and mental - for those who do not have access to communication tools impede their ability to function and participate. Quality of life is severely compromised, leaving no option to live independently, impacting on life expectancy and with increased chronic illness of the individual, vulnerability to secondary illnesses such as depression and thrombosis, withdrawal from society and community, drug addiction and/or psychosis, increased family fragility, exposure to relationship breakdowns thereby compromising establishing social networks and other informal networks, impacting the ability to contribute meaningfully to the Tasmanian economy by pursuing employment and a career, and a high risk of welfare dependency and thus a poverty crisis.

Without the essential equipment those with differing abilities cannot have the same life choices as able-bodied people. I strongly emphasise that. It is essential to emphasise that without equipment and technology aids there would be significantly increased reliance on family and care support services. For example, for an individual with mobility issues, like myself, immediately my wheelchair breaks down I am immobile. So until my wheelchair is fixed up I am bed-ridden. I am unable to move anywhere and I need to have 24-hour carer assistance and this comes at a massive cost. Basically I pay my personal care support up to $18 an hour. Agencies provide at least $36 an hour, but if it is a weekend it is $65 an hour.

Without assistive technology the individual would be at risk. In my instance, if it was going to be a long-term breakdown then I am at risk of being subjected to institutionalised care, such as a nursing home, which does provide in the long term for governments to provide ongoing recurrent funding for carer support. Reliance on carer support is increasingly difficult because of skill shortages and society not valuing that caring for others is a prosperous career choice.

Not providing assistive technology is detrimental to the health and wellbeing not only of the individual and the family unit but also to the economy and society. Individuals with mobility issues, such as myself, would not be able to have a quality of life, dreams and hopes, just like able-bodied people can. Access Economics recently conducted a report on the cost of muscular dystrophy and released it in October 2007. It states that:

> 'People with muscular dystrophy and their families and carers frequently require assistance with mobility, communication and other activities for daily living. Wheelchairs, walkers and splints, ramps, showering aids and bathing aids are still financed largely out of the pocket of people with muscular dystrophy and their families and carers.'

Additional to this, people with differing abilities also have identified that transport options must be included as an assistive tool. To purchase adaptive transport vehicles is in excess of $70 000 and that is without on-road costs. As a woman with limb-girdle muscular dystrophy, which is a degenerative condition of the muscles and limits my physical mobility, assistive equipment contributes to the following benefits. I am able to live in my home on my own. It limits my hours required for personal care assistance. It gives me the freedom to pursue a career option. I am currently full-time employed, thus I am contributing to the economy. It allows me participate fully in my community as an active volunteer and social member. It improves my choices. It allows me to establish social networks. It provides me with a quality of life and it promotes social inclusion and diversity within the community.

There was only really one clear point that I was able to address, as a person with a different ability, to this inquiry and that was point 1 - strategies, policies and practices. I want to firstly talk about the current and future resourcing. It is vital that the CES is generously funded to ensure that all people have access to essential equipment to minimise their personal care support and increase their independence at home and within the community. By doing so, it alleviates pressures on health institutions, service providers and government funding such as personal support funding. The process, however, of securing updated, reliable and functioning equipment is ad hoc. There is no one-stop shop that provides efficient and fast assessment service. Access to funding of equipment is fragmented; that is, it is shared by State, community, charity and self. Delays in the application process, because there are not enough funds, causes unfair and unjust emotional pressures and physical harm to the individual. There appears to be a culture that prevails in government and, for that matter, in society that people with differing abilities are not worthy members of society and that we should be grateful for investment into the sector.

Increased assessment costs by bringing in outside consultants - this is part of the process - to perform assessments because there are not enough State-funded occupational therapists, for instance, in the Launceston General Hospital. The consumer is not aware of the entire process and how the approval process and the actual system work.

There are identified gaps in the ongoing repair and maintenance of assistive technology: when equipment breaks down because of age or unexpected events and there is no seven-day service to assist in such times of need. This has severe ramifications on personal care support and life participation. Regular servicing of equipment according to manufacturer requirements is not always complied with. Breakdown of equipment awaiting approval for repairs impacts on the emotional and physical health of the consumer and their families because they are constantly told there is not enough funding, thus physical support falls on the carer or the family. It is really stressful when you need to wait three or four days for an approval process to go through a system that you are not familiar with and do not understand and if the equipment belongs to the service provider, for instance. Not knowing when you are going to be able to get back to work or back on your feet is an awful experience.

Equipment, with age and high use, constantly breaks down and no longer provides the essential functions it is designed to do and thus impacts on the physical wellbeing of the consumer. The process to replace it is ad hoc and stressful. Equipment such as powered wheelchairs need to be replaced after three years to ensure that equipment is suitable for the consumer and to ensure health and quality of life. Ongoing maintenance of equipment must be funded by the public purse.

I wanted to make an interpretation of the caps on contributions. I did not quite understand it. I understand that people who have equipment through the Community Equipment Scheme pay an annual fee of $50. I have just spent nine years living and working in Western Australia and the consumer does not pay a levy or an annual fee for equipment.

I have a number of recommendations. To promote quality of life, participation, self-determination and responsibility, government must provide the essential tools for those with differing abilities - such as funding essential equipment and aids on an as-needs basis. I recommend that an annual levy or fee is not imposed on those with long-term differing abilities and that adaptive assistive equipment is provided primarily by government, who can raise funds through various incentive programs. Research must be conducted to provide the quantitative and qualitative evidence that proves to government that expenditure into the provision of essential equipment for people with differing abilities is good social and economic policy in comparison to alternative options such as institutionalised care, personal care supports where these can be avoided.

A seven-day breakdown service must be established to avoid over-expenditure of repairs and ensure that compliance of repairs is adhered to. Recently my wheelchair broke down on the Saturday morning - it just would not work at all - and I had no choice but to ring up only one provider that works on weekends and, fortunately, I had lent him my second-hand wheelchair as a gesture to also help with other people who might have needed the use of a replacement chair in times of breakdown.

This business charges at a pensioner discount rate $69.50 an hour for labour. I was unable to go to the 2020 summit, which I wanted to go to, and I was unable to do anything at all on the weekend. So I had to wait until the Monday, and even then I had to wait for three days to find out whether the chair would be able to succumb to a $1 000 piece of equipment to get it up on the road again. To me, I would have demanded a second opinion and it would have been for an assessment and there has to be quick turnaround as well.

In Western Australia is that there is a seven-day, 24-hour breakdown service and it is shared amongst most businesses that are able to repair wheelchairs - not a lot but there are a few of them -

CHAIR - Like a roster system.

Ms WARDLAW - It is like a roster system, similar to what you have with Telstra and their telephone boxes. When it is not a private business, you are able to think laterally and outside the box without wanting to make money from a potential repair. So there is something there for us to consider as well.

Moving onto more solutions: I think that we should introduce a government no-interest loan scheme for consumers to perform home modifications or purchase one-off assistive equipment and aids to support independent living. So as a full-time working employee of an organisation - a career woman - I would be quite happy if I were allowed to take out a no-interest loan from the Government to purchase a height-adjustable bed which provides me with independence.

I think that we should introduce taxation incentives to the general public who invest in equipment and aid technology to support or sponsor an individual with equipment needs. It is time for our community to invest back into its community but we must be careful. People with differing abilities are not charity cases.

It is time for us to introduce a taxation reform relevant to people with differing abilities who purchase assistive equipment and aids. We should consider increased allocation of equipment funding from government enterprise businesses, such as income raised through Betfair and TabCorp. In Western Australia the Lotterywest organisation, which raises its funding through gambling, runs and funds various programs for diversified equipment - for example, height adjustable beds or hydraulic loo seats or the funds for mechanical things to help people get their wheelchairs in and out of their vehicles. I believe that we need to have a greater investment from our gambling and government business enterprises into the disability sector.

We should consider fund-assisted modifications to vehicles in place of the taxi users subsidy scheme for individuals who want to have their own car. Western Australia actually provides people with long-term disabilities with a 75 per cent subsidy scheme, which means that the user pays only 25 per cent.

Mr WHITELEY - If they call a taxi?

Ms WARDLAW - Yes. Then if that person chooses to, that money can be used to assist them in purchasing a vehicle with its modifications in place of a taxi user subsidy scheme.

Mr WHITELEY - So they can make a choice? It is either you have that or that - not both.

Ms WARDLAW - Yes. There is a lot of freedom in having your own car, let me tell you, and being able to get around. There is nothing worse than relying on taxis.

In conclusion, the provision of assistive technologies, aids and equipment to people with differing abilities is not a burden to the public purse. Rather, it is responsible government in ensuring that the correct tools are provided and maintained to a vulnerable group to ensure their functionality, participation and independence. The provision and maintenance of essential aids, equipment and assistive technology ensures that people with differing abilities are able to become more self-determining and responsible for their own communities and their futures. All governments must vigorously defend the stand that people of differing abilities are valued members of society.

This submission was jointly put together with intellectual input from my two sisters, who are also in wheelchairs and they have been in wheelchairs a lot longer than I have and they live in various States. So I really wanted to make a stand that people with differing abilities do contribute to our way of life. We are very important. We bring the intangible benefits that you may not be able to put a dollar figure on - people with differing abilities bring out the best in us as human beings.

CHAIR - Thanks very much for your submission, Jane, it is excellent.

Mr BEST - Yes, I thought, very good initiatives that you put forward there and whilst we have them on *Hansard*, I wrote a few of them down. I get a lot of constituents in the office on different issues and I had a constituent who was a contractor. He had an accident that was unrelated to the work that he was doing with a GBE. However, because he was wheelchair-bound, the GBE basically said, 'No, we do not want you any more' - pretty much along those lines, although it did not really come out that way, if you know what I mean. We worked through quite a number of issues but finally got him back as a contractor. He is in a wheelchair and does work that probably most people would not think someone in a wheelchair could do because it is physical.

I am interested in how you would see that view changing - that is, the view of people with less ability, of their worthiness or their inability to contribute to society. How would you see that view changing?

Ms WARDLAW - First of all, it is differing abilities, not less ability, if you do not mind my correcting you - it does not mean that we have any less ability.

Mr WHITELEY - I think he was referring to the perception of that. That is not his view.

Mr BEST - No, this is not my view. I am just saying -

Mr WHITELEY - But that is the perception?

Ms WARDLAW - That is all right, I am just clarifying definitions. I do not know whether that is the business of this inquiry. But to very quickly summarise it, I believe that the Labor Government State disability framework is meant to address those issues and recently I was asked to present at a forum that was designed to encourage managers of State government departments to accept and employ people with disabilities and I must say that when I walked away - so to speak - I was furious. I was absolutely gobsmacked that in this State we do not value people with disabilities as having the same capacity to think and perform duties as everybody else. So I think the way to go about solving that problem is to make it an all-level of government responsibility. I think that it goes from local government up to Federal Government. I think that we need to start having more diversified cultural programs and I think that the local government has an enormous contribution to that. Launceston, for instance, does not run a cultural program. I went to see them about some ideas about how we could build diversity within our community with some capacity building programs, and the meeting was over and done with within about six minutes as they felt it was a State government responsibility.

I think that if we could show some leadership through government about yes, it is great to put these State frameworks together however the delivery and implementation of those grandiose plans needs some working on.

Mr BEST - Sure. I will just finish off -

Ms WARDLAW - I hope you don't mind my grandstanding there. I have been dying to say that for some time!

Laughter.

Mr WHITELEY - Members of parliament wouldn't know what grandstanding was!

Laughter.

Mr BEST - I raised that in the context of the point that you make about providing the tools and those sorts of things and I suppose I said 'entwined'. I understand what the terms of reference are because I was involved in setting that up, but it is an important component, from what you have said. Just on that, do you have any information about some of those diversified cultural programs? Is there any information that you have on it as interesting reading?

Ms WARDLAW - There is a fair bit of intellectual property there and I think that that might be something that I would like to pursue but I do not know whether those diversified programs - I do not mind sharing them but I do not know -

Mr BEST - We treat things on this committee as commercial-in-confidence, but it is not a big deal. Even just an outline in the sense of just thinking about the concept of how that might change and effect some of the things that you are putting forward. That is all I was thinking about.

Ms WARDLAW - With respect, the Disability Bureau was set up to deliver that State Disability Framework and I have written to the Premier asking to have more information and willingness to espouse some cultural programs. The Disability Bureau was meant to get back in touch with me and I still have not heard back from them.

Mr BEST - What has that got to do with me as a committee member?

Ms WARDLAW - I am just saying that I feel that the Disability Bureau are funded to deliver the implementation and diversity of the programs and I am more than willing to share some of their ideas through that avenue.

Mr WHITELEY - There is a lot of talk about lack of skills in the economy. Have you found any anecdotal or researched evidence that would suggest that a far more, what shall I say, positive approach to those with differing abilities in getting them up and away with the equipment that they need would go some way to assist some of the skill shortfalls that we talk about so often? Are people, with great respect, sitting out there because of a lack of assistive technology that could be helping them make a much greater contribution? Is there anything that you have discovered or any research that would say that?

Ms WARDLAW - Last year I was contracted to do an anthropological review on one of the non-profit organisations that provides services to younger people with disabilities and I have to say coming from Western Australia I was completely and utterly floored at the level of equipment provided to those people who had to attend a day centre service. They were perfectly capable of being in the work force but the level and standard of personal care was clearly atrocious, their living standards were clearly disturbing and their lack of updated equipment to assist them with their communication skills and for them to access was also a hindrance. So yes, I do feel that there needs to be some really big investigations about -

Mr WHITELEY - Because there could be a massive human resource out there not being tapped.

Ms WARDLAW - Definitely. But I think Mr Best did bring up a point. To share intellectual property is not so easy as doing that. Sometimes to articulate what I would like to see happen here in the State is much broader than just people with differing abilities. I can send something to you.

Mr BEST - That is okay.

Ms WARDLAW - But I do think it needs to go hand in hand with the cultural attitudes of the broader community and in particular the business and government community as well that people with differing abilities are quite clever and they have a lot to contribute. I find it really disturbing when I go to an expo that is about promoting people with disabilities to get into the work force and here are young men with clearly some intellectual challenges, but really lovely people, folding cardboard boxes. I think they would be great working in an environmental land-care project. Has anyone done an audit on what it is they would like to do, where they would like to work, where they can earn a bit more money than, say, the $2.50 per hour? These are all considerations.

Ms PUTT - On the big-picture issue that we are all on now about people with differing abilities, I guess this Disability Framework for Action was about employing more people with disabilities within government departments. You have probably noticed over the last couple of years at the Estimates committees I have asked every department how many people with disabilities they are employing now and how many they were before. The interesting thing is that some can tell me and some can't and some of the ones that can't, don't, including the Health department because they say, 'We wouldn't ask somebody that. That would offend them'. I can understand where they get that apprehension from but the question in my mind is how can you know you are looking at employing more people with differing abilities and how can you understand what their needs are and provide for them if you are not even prepared to make that basic inquiry in some way? Given what we are looking at here, it flows on to whether there is a role for government departments and employers to in some degree come to the party in relation to work-related equipment if they are going to employ people? It has just popped into my head, I do not know all the issues around it, but I thought I should ask you that.

I have another basic, practical question arising from something else that you said.

Mr WARDLAW - First of all, I used to work for the State Government in Western Australia and I worked in regional development for nine years. So I have worked with vulnerable groups, not people with differing abilities, although I did a lot of voluntary stuff, but I used to work with Aboriginal and non-Aboriginal communities.

The Western Australian State Government did an audit over all their government businesses. It was along the lines of having a cultural diversity program established within the ethos of the Government at the time. They had a cultural development unit and one of their things was how to consult effectively with people because they needed to also ascertain how many people of Aboriginal descent were also working in government. So I do not see why it has to be a big issue. I think it is an accountable process and I think if we are looking at transparent and accountable governance, then I do not see why it is such a big deal.

Ms PUTT - It would seem to me that it should not have to be people with differing abilities who have to drive this all the time. That was the thing that really got up my nose about it, amongst other things.

You talked about ageing equipment and the replacement process and it ending up being ad hoc and stressful. Does that mean that if someone's equipment fails they have to demonstrate a period without the equipment and all the ensuing problems before they get a replacement? Is there no automatic process of a decision to replace?

Ms WARDLAW - No, that has to go through because there is a shortage of staff. This is what I understand. Because there is a shortage of staff that does the actual assessment process at the moment then you have time delays. I think that they try to do the very best that they can but they are humanly resourced very minimally. I think that the delays come about not out of vindictiveness or anything like that but because there are not enough people there and it has to go through an approval process. Does that make any sense?

Ms PUTT - Yes.

Ms WARDLAW - Sometimes if the person who is the decision maker is not in the office then you are going to have to wait 12 hours or 24 hours until they are back in the office or they have to run around and find somebody else.

Ms PUTT - If we are in a situation that we were hearing about earlier with $6 000 for a month for the north of the State and you have an expensive wheelchair and it just comes to the end of its life then do you have to go somewhere in that queue for that $6 000?

CHAIR - I think there is an emergency allocation.

Ms PUTT - Or is that automatically provided for?

Ms WARDLAW - There must be an emergency allocation, hopefully. I have always had my wheelchair fixed, but it has taken time and I must make comment, too, that apparently there has been a major cash injection from Treasury into the Community Equipment Scheme and I am very fortunate that I am one of those happy recipients. I have been through the process of being assessed and I will say that I love dealing with professionals but do I really need two from St Giles, one from Hobart and one from Launceston to come and assess me? That concerns me. Where we should have State government occupational therapists, why are we outsourcing? God only knows how much St Giles will be charging the health sector for two of their staff to come and assess me in a wheelchair. In Western Australia I had such a good relationship with my one occupational therapist department within the regional hospital that it only took one person to assess me, not four. There are some inefficiencies.

Mrs BUTLER - Jane, I have very much enjoyed what you have had to stay, thank you. It has had a lot of impact.

Ms WARDLAW - Thanks.

Mrs BUTLER - I wondered if you would like to comment further on some of your statements about drug addiction, psychoses, family breakdown, et cetera? It is a very broad question but can you make some contribution about what governments would do in regard to assistive technologies in relation to those sorts of social impacts?

Ms WARDLAW - I am imagining the individuals and the families who require technology, for instance, and I guess I can very briefly tell you about a personal experience of mine. I have a degenerative condition, as I have pointed out to you before. Back in the late 1990s my condition was progressively getting worse and I refused to have a wheelchair for a while. It is very difficult trying to accept the fact that you have a progressive condition. It is bad enough that we all worry about getting old let alone speeding it up by having a progressive condition. Because I did not know how to go about getting a wheelchair, I did not know who to see and I was having all this trouble about accepting my condition as well, I found that my social networks were getting smaller and smaller. I could just make it to my job, but with a lot of struggle. I would be able to get around the office, get out of my chair and so forth, and I was finding that I was falling over a lot more. I did not realise it at the time but I think depression was starting to set in. Fortunately, I have a wonderful mother and in a year or two down the track we were able to turn things around and so forth.

I understand that there are many people out there who may have a sibling with a differing ability that is very difficult for them to cope with emotionally, financially and mentally because they feel very isolated and there is no support so some of your activities could be about getting people together more. The pressures on them are enormous but that can be alleviated by having the adaptive assistive technology to help them. That means that mum might be able to go to work because Josephine now has a wheelchair that is suitable for her and she might be able to access school properly. The pressures on family and individuals are very great.

CHAIR - Thanks very much, Jane. Your submission has been more than interesting.

<u>THE WITNESS WITHDREW</u>.

Ms BELINDA HANSON, MANAGER, AND **Ms ROBYN HANSON**, NEW HORIZONS CLUB INC, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

Ms BELINDA HANSON - Robyn and myself are both from New Horizons Club. New Horizons Club provides sport and recreation opportunities for people with disabilities. Our aim is to focus on the abilities of people, not the stigma of what people cannot do, so we focus on what people can do. We increase self-esteem, sense of worth and quality of life for people with disabilities. Our young members go out to schools and we hear lots of comments about the fact that people now have a real sense of worth in their life and actually have things to talk about at lunch time and so forth. So that is our whole purpose.

Today we wanted to focus on point 2 in the terms of reference: the ability of people with disability to access funds for equipment and assistive technology. One of the major constraints is the inability to access appropriate and often expensive equipment that assists people with disabilities to join in our sport and recreation activities - things such as a track and field throwing chair in which they can be seated in to throw shot put, discus and participate in a dignified manner.

We have sports wheelchairs which are 10 years old now and falling apart. We are desperate for funding to purchase more wheelchairs for things such as wheelchair basketball, 100-metre sprints and tennis. Our wheelchair program goes around all the schools. They are nearly booked out for the full school term. That is a great opportunity for the people with disabilities in those schools to be on an even playing field with mainstream athletes. Everyone gets put in a wheelchair and plays basketball and so they are all on an equal playing field. Some schools also do awareness programs. Students will be placed in them for a full week so that everything they do, whether it is going to the bathroom or going out for lunch, they have to do in these sports wheelchairs, which does provide great awareness and it is a really great program.

Mr WHITELEY - Do you operate in the north?

Ms BELINDA HANSON - We are in the north. George Town and Scottsdale have volunteer groups. We did have one in St Helens but due to lack of volunteers it has fallen down. I have had a lady contact me recently so we want to get that up and going again.

Mr WHITELEY - Good.

Mr BEST - With the track and field chairs, is that something you can share?

Ms ROBYN HANSON - The whole thing we are talking about, particularly with the New Horizon Club equipment funding, is that it would be program where we would monitor it and it would be available for people to use. Rather than one or two being able to use it, it is an ongoing thing. It is like wheelchairs - they go statewide.

Ms PUTT - So you have funded equipment and different groups of people use it?

Ms BELINDA HANSON - Yes we do. With these other pieces of equipment that we would love to have, we find it would be important to be at a club like ours - all in one place so that people could have access, rather than an individual having a throwing chair that may be used for a short time.

Mr BEST - I am aware on the north-west coast that a cycling club has a whole heap of track bikes for young people to use. I can see the same thing - a piece of sporting equipment that everyone can use. It is a good idea.

Ms ROBYN HANSON - We have one throwing chair that we had made before the Barcelona Paralympics. We had that made because we had somebody who was a cerebral palsy athlete and we wanted to see whether he could get to qualifying standards. It is very heavy but it is utilised. I have taken it to the Australian Institute of Sport in Canberra and we utilised it there. There are much better lightweight ones that we could take around. Leroy Court used our throwing chair after he had that big accident after being a paralympian. He came to get the chair and utilised it and then started into throwing and went to the national championships. So we have one of those, which is a big heavy thing. It is a matter of athletes within schools being able to utilise that equipment and then finding out, yes, this suits me and I am good at it and it is somewhere I can go to. Then they go on and get one made specifically for themselves.

CHAIR - How are you funded? What support do you receive from the State Government?

Ms ROBYN HANSON - We are part-funded from the Department of Health and Human Services.

CHAIR - To what extent?

Ms BELINDA HANSON - We started in 1986 and the funding was one full-time member and a 15 hours part-time assistant. We had about 28 members then and we have more than 300 now - and get the same funding.

Ms ROBYN HANSON - It has increased to about $70 000 a year.

Ms BELINDA HANSON - Around $70 000 a year.

Ms ROBYN HANSON - Most of our work is done by volunteers.

Mr WHITELEY - I suppose you fundraise?

Ms BELINDA HANSON - Fundraising, applying for grants and corporate sponsorship and things like that because we now have a building. Our Great Western Tiers Cycle Challenge, an event we have run over the last few years, is our major fundraiser and it paid off our mortgage, so that has been a great help. The whole running costs of the building and providing activities is all by fundraising.

CHAIR - Does the Tasmanian Community Fund provide you with the house?

Ms ROBYN HANSON - They provided two $50 000 grants. We were very fortunate; we got that place, which was run down and people said should be flattened, just before the boom so we did get it at a very good price. It is worth a lot more.

Mr BEST - Where are you placed?

Ms ROBYN HANSON - In Mowbray.

Mr BEST - How long has it been?

Ms ROBYN HANSON - Twenty-two years. We are the only organisation of its type within Tasmania providing sport and recreation for people with disabilities.

CHAIR - Are there other New Horizons clubs or similar sporting organisations within Australia?

Ms ROBYN HANSON - There is not a similar organisation. There is nothing like our club, which primarily focuses on sport and recreation.

Mr BEST - Yours is more about sport.

Ms ROBYN HANSON - Yes. We focus on people with disabilities having the opportunity to be athletes and to be recognised as athletes.

Mr WHITELEY - To have a crack at it anyway. Like you said, most of them probably get to a point they will say, 'Great, I can actually do this. I can pursue this as something pretty significant'.

Ms BELINDA HANSON - We have other activities like craft or song and dance for members who do not have any interest in sport. Most of our members love music and acting and those sorts of things. We also take members away for trips. There is a tenpin going away, but half of the time they are doing holiday things as well. A lot of our members never get to go on a holiday.

Mr WHITELEY - What percentage of your 300 members would be sportspeople?

Ms BELINDA HANSON - About 85 per cent, but a lot do both.

Ms PUTT - So at the moment there is just nothing in the Community Equipment Scheme to cope with this type of situation at all?

Ms ROBYN HANSON - No.

Mr WHITELEY - It would not even fit the criteria?

Ms ROBYN HANSON - No. What we were aiming at particularly is the more physically disabled. Someone came in just recently with a 12-year-old child with severe autism, asking whether there was there anything for them. Quite a lot of times, over my years there, parents have said, 'My child cannot do that'. Bring them in and let us have a look, because nine out of 10 times there are activities. Look at the Paralympics. For people who are severely disabled, it is an international sport. Many people do not realise that. They do not realise the classifications of how people can compete.

We would love to get someone to make us a bowls chair. We have athletes who are physically disabled in wheelchairs. One can get up on the frame, but to come and play bowls they have to either get down on the floor or they cannot bowl properly because you have big wheels. I can visualise a chair where they could sit on it, maybe with two smaller back wheels, just to move them to one you seat them in, but without wheels so that you can coach them to bowl properly. They do not have to be undignified and hold up people because it takes time.

I can remember when we first started going. We would get invitations to take our members to bowling in the community. The warm fuzzy thing happened and they would say, 'Aren't they wonderful', and all these things. That is not what we were after. We were after them to bowl and take their place. Then they joined and went into the regular roster and we had volunteers to support them. All of a sudden they started to win and then questions were asked about whether he had his hand over the line.

Laughter.

Ms ROBYN HANSON - This intellectually disabled person is telling that person where to bowl. Only the skipper can do that but that person who is telling the disabled person would not have any idea where he was to go but, yes, once he got it, he will be paying -

Ms PUTT - Human nature is lovely, isn't it?

Laughter.

Mr WHITELEY - If the magic wand was passed to you, as it was passed earlier, then what would you like to see, in the ultimate sense, to assist the people you are serving - a pool of specially identified funds?

Ms BELINDA HANSON - Yes, I think so. Obviously there are funds that we could put into lots of different areas but I think it could be a specifically identified group of funds. There may even be some equipment out there that could be audited over the State and brought into one place so that the equipment that is there and then funds could be brought into one place and it could be made known to everyone that that is where it is. If they need anything or if schools have a student who needs some form of equipment, they know where to go rather than having to come out with a $5 000 chair just to do something they might only want to do once - they do not get a chance to trial it.

Ms ROBYN HANSON - We need to upgrade our chairs. We have 10 sports wheelchairs. We need at least another five so that we can then work on the others to bring them up to scratch - they are sensor chairs - when people require them and the schools require them for students. We really need an initial grant for that particular thing, for five, say, sports wheelchairs, but a recurring grant of, say, $10 000 added to our small funding, we guess -

Mr WHITELEY - Can we just go back one step - to catch up on that one-off, the five extra or whatever, what sort of dollars are we talking about?

Ms BELINDA HANSON - Each sports wheelchair is approximately $4 000.

Mr BEST - Is that all? I mean, it is a lot of money for them.

Ms ROBYN HANSON - Last time we had them done, the paralympian, Paul Wiggins, was it -

Ms BELINDA HANSON - Paul Wiggins, yes.

Ms ROBYN HANSON - He brought the parts in and he made them for us so it was quite a lot cheaper than it would have cost us - and we had 10.

Mr WHITELEY - Are they tax deductable?

Ms BELINDA HANSON - Yes.

Mr BEST - Can you play basketball and things like that in these wheelchairs?

Ms BELINDA HANSON - Yes.

Mr BEST - So they are multipurpose ones?

Ms ROBYN HANSON - Yes.

Ms BELINDA HANSON - Yes, basketball, tennis.

CHAIR - Do you have submissions in to the Tasmanian Community Fund?

Ms ROBYN HANSON - They gave us $10 000 when we were doing our renovations throughout the property.

CHAIR - Is that Winifred Booth?

Ms ROBYN HANSON - Yes, we have not had any further funding.

CHAIR - Regarding the Tasmanian Community Fund, do you think you can go to the well again? This sounds like a good project that they might take on.

Mr WHITELEY - Have you received money in the past from the Tasmanian Community Fund?

Ms ROBYN HANSON - Yes, they assist us with the house.

Mr WHITELEY - Sorry, you did say that.

Mr BEST - Now they have an ongoing thing.

Ms ROBYN HANSON - There are certainly possibilities that we can try but ongoing funding to be able to keep equipment up would be such a benefit.

Mr BEST - Yes.

Ms BELINDA HANSON - Another thing that is an issue is some of our swimmers have a great deal of difficulty getting into the pool. They love it once they are in there. So at the moment our volunteers are physically lifting them in and getting them out. It is not great for our volunteers to be doing that and it is not easy for them.

Mr WHITELEY - Have you had any input into the new pool?

Ms ROBYN HANSON -Yes, a letter was sent so we are hoping that there is going to be a lifting device there.

Ms BELINDA HANSON - We expect it to be there, yes.

Mr WHITELEY - Out of $20-odd million, you would hope they would fix that little matter. Irrespective of that, there are other pools around that no doubt people are using.

Ms BELINDA HANSON - Yes, that is right. If there was device that they could fit into, mould into.

Mr WHITELEY - And they are not that expensive, are they, those things that hang off the side? I could not imagine that would be massively expensive. But for you, every $1 000 is a lot of money. I accept that.

Ms ROBYN HANSON - Yes, it is. Most of our athletes are involved in special Olympics. In the recent junior games, 18 went - 16 from the north. They were all our New Horizons basic members.

CHAIR - Robyn and Belinda, do you see a bigger role for New Horizons in the community? Do you feel that you might need to expand your responsibilities to perhaps pick up some slack that is not coming from other areas?

Ms ROBYN HANSON - That has been an issue. We have been approached by Hobart before when I was managing -

Mr WHITELEY - To take this model down there?

Ms ROBYN HANSON - to have New Horizons down there.

CHAIR - When you say 'Hobart', what do you mean, people in the community or the Government?

Ms ROBYN HANSON - Yes, people in the community. We quite often have phone calls, 'Is there an organisation like yours? Can my son and daughter go to an organisation like that?', and the answer is no. Unless we received a whole big batch of money and could start up an office, it is not practical to do what we have. But the need is definitely there.

Self-esteem is developed and a sense of worth. The person that comes in feels they are a nothing or a nobody and they cannot do it until after they have been involved. A lot of them have become leaders within our club.

Mr BEST - Yes, life-changing.

Ms ROBYN HANSON - They are running their own lives and know 'I am somebody, I can do things'.

CHAIR - Had you met Jane Wardlaw before?

Ms BELINDA HANSON - I have.

Ms ROBYN HANSON - No, I haven't.

Ms BELINDA HANSON - Only briefly though.

We go out into the schools and run Come and Try Day. We will go to one school and invite all the other schools to come with any members of their school that have any sort of disability or learning difficulty and they come and have a great day. Then we get phone calls asking if we could go into the schools. Summerdale has about 26 students and would love us to go and run their Friday sports because they have found these students in the schools are not fitting into the Friday sport program. But the ideal situation would be for them to go off to their sport at the same time and they would love for us to go and present and take the Friday sport, which we would love to do.

I am trying to round up enough volunteers to do a six-week bloc but our staffing limits doing this because obviously we only have myself as a full-timer and a 15-hour assistant - I could spend 9 to 5 writing grant applications all the time - but there are all these other opportunities that are out there that are lacking in the community that would great. But we have a lack of staff and obviously a lot of our volunteers work so in that Friday sport time there is not a great number of volunteers for us to go out into schools and do that, but we do our best. We need more funding to get more employees and cater for these needs that are in the community.

Ms ROBYN HANSON - When we started up the club we found that many of the intellectually disabled young men that we got involved in sport and were quite good at sport were also very vulnerable to getting involved in criminal activities because they were easily conned, they were looking for friendship, the guys knew of their disability. We had several and it changed their lives around because, all of a sudden, they felt they were good at it and they started to help those less capable as well so it certainly decreased criminal activity amongst a number of our young men that became involved and they felt a sense of worth. They found friends within their sport and within their group. In the early days Verne Spence was involved in the club and he visited the police station a couple of times.

Mr WHITELEY - You are doing a great job. I was aware of the organisation but I didn't realise you were servicing - is that the right word? - so many people. That is just extraordinary.

CHAIR - Yes. Of course, there are the members and then there are the volunteers so it is quite a big family.

Ms ROBYN HANSON - A lot of the parents there have changed too. Some of those have become volunteers and some have even become coaches. We got one young man involved a couple of years ago and the parents were really worried about suicide. The next thing he was representing Australia in New Zealand and he won the award for about two or three sports this year. We were able to connect him up with friends that had a gardening business and he got a job. He got a girlfriend and he is going great guns now.

Mr WHITELEY - That is great.

CHAIR - Are you not able to pursue advocacy work within your organisation because of that lack of funding? Do you feel that there could be an opportunity for you to do more if you were able to take on some of the bigger issues of the people who come to you?

Ms BELINDA HANSON - Definitely.

Ms ROBYN HANSON - There is a lot more to be done but there are only so many hours in a day and so many people to do it.

Ms BELINDA HANSON - We have big dreams and aspirations. It is just a matter of time and resources and people really to be able to achieve it all. With a lot of our families, the parents get respite if the athletes are coming with us. Even if it is an hour, they have an hour to themselves which a lot of our parents do not get. Or if we take them away on a camping trip or they go away for a weekend sport, they have a weekend to themselves. So it is a form of respite as well.

Ms ROBYN HANSON - A lot of our volunteers pay their own way to do that. The group homes that have the clients that come with us do not have to have the staffing, but we cannot get one of the staff to come with them.

Mr WHITELEY - That is very interesting. So it is an opportunity for them to save money?

Ms ROBYN HANSON - We have had to get a volunteer, some kind of nurse or whatever, if we do not have that person to take with us.

Ms BELINDA HANSON - A lot of the group home members are the higher-needs members and it is a big strain on our volunteers that are going along to look after them. So we have requested that they send one with their five members that are coming along. But they never will because they do not have to pay anyone if they are coming along with us.

Ms ROBYN HANSON - The Scottsdale group meet once a week on a Monday and there are about eight to 10 from the day care centre that come and they do sport and recreation. Some of it is very minimal but they get out. They provide the bus and drive them over to the Scottsdale gym, and that has been happening for many years now.

Mr WHITELEY - Terrific.

CHAIR - Thanks Belinda and Robyn very much for joining us here today. I think we have the information that we need on *Hansard*.

THE WITNESSES WITHDREW.

Mr CLIVE STOTT WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Mr Finch) - Thank you very much for joining us here today and we are pleased you could be with us. We have had some wonderful evidence through the morning and I am sure you will be compelling to listen to as well. Would you like to, Clive, take the floor and present your information and then we will ask questions of you.

Mr STOTT - Sure, and please ask questions as we go along. I am here on my own, as you can see, but that just happens to be the nature of what I am going to raise today - people with respiratory disabilities. Just on that matter, I would like to give you my background. I actually thought that my submission was out of date and I would not even be included so I thank you for letting me come along today to have a talk.

I worked in State Health for approximately 15 years in charge of hospital biomedical engineering and in hospital engineering at the Scottsdale Hospital. That is a rural hospital and being in charge of that meant you were in charge of nearly every department. I used to train the doctors in the biomedical equipment. I used to train the nurses on all the new equipment that came in. I set up CSSD and all those sorts of things and all the theatre equipment, et cetera, plus all the buildings and any other equipment around and all the outlying equipment. Not only that, I knew nearly everybody I was dealing with because they were all part of that community.

It was all hands on. The hospital used to do oxygen therapy for the patients in the north-east. That was done by the State Health and then they said they would not do it. I had people ringing me up asking what was going on so I personally took on doing all the respiratory equipment and servicing for BOC - CIG at that stage - going right out to Gladstone and doing all that sort of thing for them. But I think the real reason that pushed me on with that and also to go into the hospital environment was that I have been a life-long asthmatic. They do not know whether it is COPD now which I have found is a totally different disease.

For 60 years I have lived with that condition and I have fought it and I have beaten it - and I am still beating it. You still have to breathe. To be able to breathe sometimes we need a bit of assistance and this is really the crux of what I am here to ask for today. You will find that a lot of asthmatics, a lot of people with breathing difficulties, become very withdrawn. You will not hear me wheeze today because I am choked full of medication. I was admitted to A&E two weeks ago and I was sent home to recuperate and I am here today. But you will find that people like myself will not actually come out, they stop inside a lot, which is the worst thing, because as we know now air inside is probably two to five times worse than what it is outside. We will not mention the last three weeks that I have been battling, but you get the message I think.

People really should be out enjoying our good clean air and keeping healthy and doing things, but they do not. They stop inside with not much support and there are a few little things that could help them along the way. This is what I wanted to raise today. I have expanded a little bit on my submission and I will give you a copy if you could photocopy it and I will have one when I am finished.

I will also leave this document with you to copy. That is called a powered air respirator. That looks like an industrial model there and you would think what on earth would I want to wear that for. But believe me, I have worked in it - you use it for things like asbestos removal and dust and whatever. If I had one of those and if other people in my condition had one of those, my wife would not have to mow our lawns on the ride-on. It has been specifically designed - it is made by 3M, all good gear - and all it is is a little belt pack designed very nicely. They are the filters and it is a little air pump that gives you positive air over your face. It is a PAPR - powered air positive respirator. That aids your breathing and also filters the air. It was designed for that reason - 'Designed to be used for people with existing respiratory difficulties, e.g., asthma'.

Mr BEST - What would something like that cost?

Mr STOTT - Around $1 500.

Mr WHITELEY - It is going to last a while. The filters will need changing but the actual hard-core stuff will last.

Mr STOTT - Yes, it is designed well and it would last for years.

Ms PUTT - And is part of the thing with this that it is a portable thing.

Mr STOTT - It is portable, it is battery-operated, and it goes for about four hours.

Mr BEST - Are you suggesting something like that for a person to own or do you see things like that as being things that people would access?

Mr STOTT - It could probably be funded through Health, go into the hospital system, go into their audit and maintenance.

Mr BEST - Like a CPAT machine.

Mr STOTT - Well, it is very similar.

Mr WHITELEY - But the thing is for a lifestyle issue you do not really want to have to go and get one -

Mr STOTT - No, you would need to be issued with one.

Mr WHITELEY - Issued to keep?

Mr STOTT - Yes.

Mr BEST - But you could use it -

Mr WHITELEY - Sorry, Brenton, I misunderstood, I thought you meant go and get it and take it back.

Mr STOTT - No, it would be personal issue because it is personal protection equipment and you would not want to be sharing it. But it would be personal issue like my oxygen concentrator and if it goes into the maintenance system, then like I used to with the medical oxygen, you go out and do a service and the person is happy and that is all that would be noted.

Mr BEST - As well as enabling you to do certain things that you might not be able to do otherwise, something like that would help in general - particularly in the light of what you said about being indoors being not so good and so forth.

Mr STOTT - Yes. There are a lot of triggers that can bring my condition on. It can be mould or dust, but you can get the filters that suit all these things. Just being able to paint is a big day for me - water-based paint inside. To mow the lawn or dig the garden, if it is dusty I have to stop doing those things and people should not have to stop when there is technology about. That is what we are talking about with today's committee. That technology is about and it has been designed for -

Mr BEST - It is fairly cheap too, $300.

Mr STOTT - It is, considering.

I have to put up alternatives to be considered. You must realise that people with my condition have a lot of extra costs for medication and trips to hospital and doctors et cetera. Not only that, we have to hire somebody in to do a lot of things for us where we could be saving.

Mr WHITELEY - In your condition you would be on a disability pension?

Mr STOTT - Yes.

Mr WHITELEY - So the money is tight anyway?

Mr STOTT - Yes.

The second lot which I battle with at present is probably what you all know, it is called a half-face reusable respirator. You can get lots of different styles of these. I have found that the one that is silicone, not so much rubber, but you have to make sure that you do not have a silicone allergy so that you can wear it. The beauty of that is, it will seal around your face. You can get a good seal and this would be a problem if you wanted people to wear these because they have to be trained to do it. You put that on and you are up and running. Somebody, in their wisdom, down the track might say, 'We can save some dollars, we will give him one of these and he will happy.' But I am trained in this and I know that you have to get a positive seal inside so that you do not breathe the air down through there instead of through the filter.

Mr WHITELEY - What are they worth?

Mr STOTT - They are about $65 plus filters. But I would go through three of those a year. It does not sound much but, as we have mentioned before, it is all on top of everything else.

CHAIR - Are they not provided?

Mr STOTT - No.

Ms PUTT - Have you tried to get them provided? I am trying to ascertain what the system is when there is something new like this and you find out about it because you have an interest and an expertise. How does the system ever find out in order to be doing it?

Mr STOTT - Only by coming to places such as this. Secondly, how do the other people who have my condition know it is available?

Ms PUTT - Yes.

Mr STOTT - You would hope that it would come out in the Tasmanian Government Concession Booklet and that is issued every year.

Mr WHITELEY - You have an interest so you have pursued it.

Mr STOTT - Exactly.

Mr WHITELEY - The punter out there who would not have a clue would not even bother to think that there might be a solution to this.

Mr STOTT - No because they just do not know.

Ms PUTT - You'd think their doctors would tell them.

Mr WHITELEY - You would hope they would.

CHAIR - How many people do you think might benefit, Clive, what is your guesstimate?

Mr STOTT - That is a bit like 'how long is a bit of string?' I was prepared for that question. This morning I was on the Internet and I have been on there before trying to get some facts and figures. Would you believe that the asthma web site has so much outdated information with regard to statistics? But it will give you what I have. With regard to COPD: across the Australian community a conservatively estimated $815 million to $895 million in 2000-01. Inclusion of hidden costs, such as management of complication morbidity associated with COPD would bump the figure up to more than $1 billion. With regard to asthma: 12 per cent of the population leading to nearly 40 000 hospitalisations. Every time that somebody wore one of these, it would hopefully prevent them being hospitalised.

Mr WHITELEY - It does not get any more expensive than when you walk through the door of A&E.

Mr STOTT - When I was admitted the other day, goodness knows, I was there for eight hours on everything they could put me on. My wife drove me in, so I saved ambulance costs. There is the medical oxygen, the staff - everything. It is costly.

CHAIR - But how would you get yourself into that situation? How can this alleviate that situation that you are talking about?

Mr STOTT - I do not want to get political here, but it was wood smoke that caused my condition the other day. I battled it for four or five days and then with all the medication that was available to me for home use, which is everything they can get me hospital, I could not manage any more. If I had that then, when I went outside to do anything, I could have put it on and prevented that wood smoke from triggering and exacerbating that condition.

CHAIR - You do not have that equipment now?

Mr STOTT - The problem is that I have one of these that I keep buying because it wears out. Being on limited finances, you try to stretch the filter life, which is absolutely the wrong thing to do. It is the cost of the consumables - being the filters - and of the mask itself that prevent you from wearing it like you should. I do not want to wear it every day, I want to get better, but while you have these exacerbations the chance of getting better is just sliding. That is pretty sad, and not only for me. When I was dealing with people with respiratory problems they would talk to me about these things. They lived out the back of Ringarooma; you knew them personally and they looked forward to your coming and supporting them. They looked forward to that every three months when I went there to service their equipment, because it was a connection. It is still being offered, of course, but in the initial instance, when it looked like they were taking it away, they were in panic mode.

I do not know the numbers to be honest. I know that you are not going to get those sorts of numbers to want to take it up because there are people who are beyond that. There are people who have missed this opportunity. There are people who now are bedridden with this. I want to manage my condition at home as long as I can and I reckon this is probably the only way.

Mrs BUTLER - Are they breakable, those half-face masks?

Mr STOTT - No, they are very strong. The worst thing that can happen is that it has a little thing that goes across the top with the elastic that comes down and meets down the side here.

Mrs BUTLER - Yes. I picked up a bloke in Queenstown and it had come apart and he had a lot of blood on his face where he cut himself.

Mr STOTT - I buy the ones that have replacement parts. I started out doing it the cheap way, like other people, but it is false economy because after one break you had to throw the whole thing away. So I bought the one that you can order every little bit for. Just that little hat bit was $15, so it is not economical anyway - like trying to build a car out of spare parts,

There is one other thing that would make an absolute difference to the majority of people, especially once they are driven indoors, and that is an air purifier. The latest technology is coming out every day. They are great things, just like a little airconditioner.

Mrs BUTLER - They are big in New Zealand.

Mr STOTT - Big everywhere - except here. They are coming, though. I got this pamphlet up in Launceston. They are selling them here now but there are better ones than that. That is just one that I found. They are getting right up to nine-stage filtration now. They are very easy to maintain; just wipe the plates inside every now and then and they are ready to go again.

Mr BEST - Similar cost to an air conditioner?

Mr STOTT - No, $400.

CHAIR - What is it called - an air purifier?

Mr STOTT - An air purifier. It has fan in it. It has an absolute filter and various stages of ionisation that attract the dirt out of the air. They come in different sizes and would need to be sized to your room. This one, I think, will do something like 30 square metres of floor space for a normal eight-foot ceiling. It gives about five changes of air an hour and purifies it. A lot of these now are being certified and tested by people like the Asthma Foundation and various respiratory places overseas. That would give a safe haven to people like myself.

The other day, when I was sent home from hospital to recover and recuperate, the house stank of smoke, the bedding stank of smoke and I could not go outside. I could not wash the bedding and put it outside because it would have come back with smoke on it. So I have been living in that for almost two weeks while the bushfires have been burning.

CHAIR - Where do you live, Clive?

Mr STOTT - Grindelwald. I moved from Scottsdale.

CHAIR - To get away from it.

Mr STOTT - To get away from it - sad, isn't it?

CHAIR - So where would that travel from to affect you at Grindelwald? From the north-east?

Mr STOTT - No. I rang the Bureau of Meteorology and they said that something like 85 per cent of prevailing weather down the Tamar Valley comes from slightly south of west to slightly east of north. My argument was how come we are getting smoke that went down the north-west last year. It did not start two weeks ago. I had this problem all last year when they were burning. According to the Bureau of Meteorology, air is deflected by the Western Tiers, funnelled around this way and back up into Launceston.

Ms PUTT - We got an expert in this whole area of airflow and particulate flow to get some satellite data from NASA in relation to the Tamar Valley. He had to go to Israel to the Hebrew University to purchase the stuff from NASA to get the satellite images of what happens. It is quite complex but very interesting.

CHAIR - Clive, I am wondering about an advocacy group. Who would be putting forward your issues to the State or Federal Governments? Is it the Asthma Foundation or are you doing it as a lone warrior?

Mr STOTT - I am doing it solely at this point. The Asthma Foundation et cetera seem to be doing a great job with training and education at that level. They could possibly pick it up, I don't know, but I have not discussed any of this with them - because of my condition. I was talking to them this morning about what was in the *Mercury* but not about this.

I would hope that something might come back from your committee to kick it off. We are fragmented, let's face it, because we are all battling this on our own. I don't think you would find that the respiratory doctors and specialists would be interested in it - that is not their game.

I would have to give that some more thought. You do need a united voice; you need to be able to raise it somewhere.

CHAIR - You have made a start here today.

Mr STOTT - I have.

Mr WHITELEY - Who would have even thought of it?

Mr STOTT - Correct. Before, when I was dealing with them, and that was a quarter of the State, you could talk to them about these things. Now I do not do that; I find just living day to day seems to be quite enough for me.

Without the use of these devices, people with breathing difficulties cannot perform everyday tasks that they should, could or would want to do. Medical research has found that people with chronic lung disease have, or go on to suffer, depression and anxiety and need added support from family, friends and the community. It impacts on the community as a whole with additional costly medications, doctors visits, ambulance calls, accidents and emergencies, having to employ carers, installing aids as you get worse - ramps and rails - and being placed on costly life-support oxygen. There is a financial cost to the families, the person and the health system. Every exacerbation that you can prevent is a plus for everybody because, believe me, for every bad one you have you really do not come back from it. That is additive. It would allow people to be more independent, increase their feeling of self-worth and prevent life-threatening episodes that result in long and lasting respiratory distress.

One in five or one in six, depending where you get your information, has childhood asthma that can be reasonably controlled in a lot of cases but it is usually with the person for life. So it is a costly and long road. I am not advocating that children should wear these. They do not even make children's sizes. I wear the smallest one there is. You hope that parents would guide kids to keep away from those triggers and look after them as best they can.

CHAIR - Thanks for your submission, Clive.

<u>THE WITNESS WITHDREW</u>.