

THE PARLIAMENTARY STANDING COMMITTEE OF COMMUNITY DEVELOPMENT MET AT HENTY HOUSE, LAUNCESTON ON WEDNESDAY 30 JUNE 2004.

INQUIRY INTO YOUNG PEOPLE WITH ACQUIRED DISABILITIES

Ms JOYCE ABLITT, PRESIDENT, AUSTRALIAN HUNTINGTON'S DISEASE ASSOCIATION (TAS.) INC.; **Ms PAM MARSHALL** AND **Ms VIV ELLIOTT**, SOCIAL WORKERS, HUNTINGTON'S DISEASE Service, LAUNCESTON GENERAL HOSPITAL, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR (Ms Thorp) - Thank you very much for taking the time to meet with us today. Could you please introduce yourselves, for the purposes of Hansard. We will then give you carte blanche to put your position to us and then we can ask questions towards the end of your submission.

Ms MARSHALL - We will start by clarifying where we fit. Joyce is the President of the Huntington's Disease Association, which is a support group working with families with Huntington's. Viv and I work for the Health department within the Huntington's Disease Service, solely with families with Huntington's Disease. So, whilst we work together on a lot of issues, we are actually government employees and Joyce is with the support association.

In summary, from our point of view, from the perspective of the service, what prompted Viv and I to respond to this was that we have a sense that our clients with Huntington's disease when they get to nursing home care level, fall through the gaps in the system. This is a gap that aged care isn't wanting necessarily to fix, or mental health or disability. So when it comes to nursing home levels, aged care is under pressure. Their brief is for aged people and aged people with disability, and our people don't quite fit. It has become particularly difficult recently. That is what really prompted us to come forward when you advertised the terms of reference.

The second issue is that when people with Huntington's need that level of care they are often in their forties or fifties and they go into aged-care facilities alongside people who are aged 80 and 90 in nursing homes that are not equipped with their activities or systems to deal with those individuals. We were talking on the way here about a good example of a client who was recently admitted to a nursing home. Her grandmother had died just prior to her admission, so she would have been in a nursing home with her grandmother. So even where they are able to access nursing home level care, it is 40 or 50-year-old people, my age and younger, who are in nursing homes with 80 and 90 year olds. It is a question of appropriate care at that point.

The third issue, from my perspective, is that some people with Huntington's suffer quite difficult symptoms; others not so much. Often there are mood and behaviour difficulties. When those symptoms are present there is even more resistance in mainstream care facilities to having people with challenging behaviours.

CHAIR - Please excuse my ignorance, but it is not a disease I am familiar with.

Ms MARSHALL - It is a genetic disease; it is neurological. Essentially it affects a small portion of the brain and causes a deterioration of physical ability, cognitive thinking ability and emotional ability, so it hits every aspect of people. It is inherited and is what is called a 'dominant' disease. A person with a parent with Huntington's has a 50 per cent chance of inheriting the disorder. So if I have a parent with Huntington's I have a 50-50 chance of getting the disease. It hits in mid-life - for various reasons in Tasmania it strikes the mid-40s, so you have had your family before you are affected.

One of the other issues with it is that, unlike some cancers and others, it takes an inordinately long time to run its course. The average life span for someone with Huntington's is 15 to 20 years. For families, they have this person declining with very difficult symptoms over a period of 15 to 20 years. Quite often marriages do not survive. While children are caring for their parents, they know that this may well be them in the future. There has been a dramatic impact on families and someone once described it as the worst disease known to man.

CHAIR - How common is it in Tasmania?

Ms MARSHALL - Worldwide it affects 300 000 people. We had a significant migration to Tasmania many years ago, in the 1830s - this was before Huntington's was even identified. That person had 13 or 14 children, as was common in those days, and most of her descendents have remained in Tasmania. We have an incidence of about 12 in 100 000, which puts us fifth in the world for Huntington's. It has nothing to do with inbreeding or two heads or all those things we are supposed to have. It is simply that this lady's descendents have remained in our State's population. A large number of the people we work with are descended from that one particular case.

Mr WILKINSON - With the advent of DNA, can they tell at an early age if you are going to contract it?

Ms MARSHALL - Not before 1993. In 1993 they identified the gene that causes it. In fact, that is my role; I do the genetic testing. Often, for people looking at it from the outside, it sounds like a godsend and everybody can go and get tested and they would then know and could have children. From the outside that is how it is perceived. Indeed, I think it is quite interesting to note the attitude of people who grew up in Huntington's families prior to the test being available. Major research around the world showed that about 80 per cent of people at risk of Huntington's indicated that they would have the test. When the test was established - it has now been going some 10 years or so - fewer than 20 per cent of people at risk are in fact tested. It is clear that the reality of coming forward for testing is quite different.

Ms HAY - Do you approach those families?

Ms MARSHALL - No, we don't. We do not see that as part of our role. The interesting thing about that, from my perspective, is that we need to accept that decision. People in Huntington's families are just like everyone around this table - politicians, social workers, doctors, nurses, lawyers. People who live in the jungle of Venezuela have the highest incidence of Huntington's. It is across countries, education groups, income groups, races. And overwhelmingly, people like us who think we might be tested choose not to be.

Ms HAY - Are we sure that they know that the test is available and what is involved?

Ms MARSHALL - Yes, absolutely.

Mr WILKINSON - So the only reason for not being tested is they are scared.

Ms MARSHALL - That is one of the thoughts that has been thrown around over the years, but I think the evidence is very much to the contrary. The evidence is that it is a philosophical life decision. My predecessor, Sandy Taylor - now Dr Sandy Taylor - did her doctorate in social work on that very issue of what makes people come forward and how they make those decisions. If you talk with families - and I am sure the others will have comments to make - they tell you things like that. I remember when I first started in this work talking to a young woman who was pregnant and was distressed because a number of people had suggested that she could or should have been tested and could or should have had the baby tested. I can remember this young woman saying to me, 'If this baby was going to be born disabled in some way or blind, I may well have contemplated termination', but, she said, 'This baby will be born well and will get 48 years of good life. After that there is a 50:50 chance that it will still go on living a good life, so what are they on about?' I think when you put yourselves in the shoes of people who have to live with this - and there is no treatment, there is no cure - you realise that they learn to live with it in their kind of way. As health professionals, we might suggest that they should or could be tested, but the reality is that you and I would most likely to choose not to be tested. The human genome may find out that we all have genetic risk and we all will be given this choice. So the Huntington's community has been quite a good example of how we might behave as a group of people and the chances are we probably will choose not to be tested.

Mr FINCH - Who does the testing, Pam? Do they do it at Clifford Craig?

Ms MARSHALL - No, Murdoch Institute in Melbourne does Tasmania's so we do it under their auspices. The laboratory work is in fact quite complicated. There aren't any laboratories in Tasmania that can do it and we do not have the financial capacity to set that up.

Mr FINCH - Is it a blood test?

Ms MARSHALL - Yes, it is a complicated blood test. The laboratory work takes eight weeks.

Mr FINCH - Do the clients need to go there or can they do it from here?

Ms MARSHALL - They do it here. Because Huntington's was the first gene discovered of a late-onset, incurable disease, the scientists, the biomedical community and these families represented by the Huntington's Association - and there is an international Huntington's Association - were terribly excited they had found the gene because research could now tackle it. It was hugely exciting, but it presented this possibility of telling someone at birth what was going to happen to them and how they were going to die in their 30s, 40s or 50s. Suicide within Huntington's families is a major issue - depression - all of that stuff is very significant, so the two communities, the medical profession and the families, got together and drew up a protocol that people had to go through if they wanted to have this genetic test. We know it as the international protocol. Wherever you go to get tested for Huntington's worldwide you have to go through a process and my role in that is to prepare people - pre-test counselling, then giving them the result and then post-test follow-up. That happens wherever you go in the world. We are now looking back at 10 years of testing and seeing how that has worked and it is coming up very well and in fact it is now being used as model. It was used as a model for AIDS testing, and it is now being used for spinocerebellar ataxia, some motorneurones, early-onset Alzheimers - there are a lot of those late-onset diseases.

Ms ELLIOTT - When you talk about people not choosing to have the test, you have to remember, as Pam has already said, that there is no cure. There are psychiatric drugs that assist when there is significant cognitive decline and that really is all that we can offer other than social support, nursing care and that sort of thing.

Ms MARSHALL - It is a good point because I think you are spot on as to what differentiates it from why I might get tested for heart disease, breast cancer or bowel cancer. I know that if I have a susceptibility to bowel or breast cancer I can eat right, I can diet, I can exercise, I can have scans, I can have mammograms - I can do all these things. I may well go and get tested for that, but do I want to know about something about which I can do very little.

Ms ELLIOTT - You can do nothing really.

Mr BEST - How do you accommodate then? What needs to happen in relation to accommodating people that acquire the disease?

Ms ELLIOTT - Until recently people would either be cared for by relatives in their home or any aged-care nursing home would accept people. I gather that you have been to Eskleigh. Eskleigh was a nursing home of choice of people with Huntington's or if the symptoms were psychotic and definitely coming under the label of mental illness too, there were issues associated with that, then they would be accommodated in the mental health system but very few people did. In the dim dark past, everybody went off to New Norfolk but thank goodness we are more enlightened these days.

Mr BEST - When you say 'by choice', to me that is an interesting concept. You say, 'Eskleigh, by choice'. I do not want to sound ignorant but what is the choice in that sense? What does that choice mean?

Ms ELLIOTT - I suppose what I was referring to is that traditionally people have chosen to go to Eskleigh. Their parents may have been there and died there and the care was such that they have said, 'If it is me, when it is my turn, I would like to go to Eskleigh.' And

until fairly recently they would perhaps negotiate entry with the management of Eskleigh.

Ms MARSHALL - Eskleigh probably developed a bit of an expertise so for people in the north that was a real option. In the north-west and the south obviously it was not an easy option for families to do that but they also had a younger clientele. It is the only nursing home in Tasmania that is under the disability umbrella so there is a younger group of people there, so there was a choice for the northerners in that sense that they were with younger people and there was some expertise there.

Mr FINCH - Are clients still going there?

Ms MARSHALL - That is political and I guess we have to be careful what we say but it seems to have come to a bit of a head in the last six months and there seems to have been a bit of a stand-off between Disability and Aged Care and Mental Health; everybody under pressure and saying, 'That is not ours.' We slotted in - we got the best out of everybody. We are now being pushed out.

Mr BEST - Does that mean you do not fit the assessment?

Ms ELLIOTT - We do not mean this in a negative way or anything about the way Eskleigh is run. I think that what has happened is that perhaps some of Huntington's clients do not fit with the existing clientele so there have been issues, so they are able to exclude people who do not fit with the clientele. Over and above that only recently - I think the beginning of this year - Disability Services have recognised Huntington's. When I say, 'recognised Huntington's', it is considered a disability and they can apply for packages and so on and support through Disability Services. Prior to that it did not happen. There has also been some connection now between Disability Services and Eskleigh as far as the gateway to Eskleigh is concerned so it is a mish-mash of all of those things really.

Mr BEST - In a way what you are saying is the support that is required for someone with Huntington's disease may be different to someone with other disabilities?

Ms ELLIOTT - Yes.

Mr BEST - Is that a big issue?

Ms ELLIOTT - Yes.

Mr BEST - It is? Would you rate that as perhaps - for your brief anyway - one of the biggest issues in a sense?

Ms ELLIOTT - I suppose it is because they have multi-needs. That is perhaps more so than the average aged or even some other disabilities. They have high needs really.

Ms MARSHALL - From the beginning of the disease, I think you could say that, not just nursing home level care. For the whole 15, 20 years, because it affects physical, emotional and cognitive. MS and Parkinson's are challenging diseases, but they tend to be physical. On top of this physical decline, you have people with a very specific form of dementia, not like normal dementia, on top of which you have depression, irritability

and explosive temper tantrums from day one. Multiple needs and specialised care is a major issue, and an appropriate nursing home -

Ms ABLITT - There is a constant need for physical and mental stimulation to maintain the level that the people are at so that they do not deteriorate as quickly. If they are stimulated it helps to keep them more active and interested and everything like that.

Ms ELLIOTT - Ideally they need perhaps specialist diversion therapy, physiotherapy and speech therapy. It also, of course, by affecting the muscles, causes involuntary movement. There is deterioration of the ability to speak and to make yourself understood. It is very difficult to nurse someone in those circumstances. Also this means levels of frustration and irritability, leading in some instances to aggression and so on. It is very high need in a nursing home situation.

Ms MARSHALL - Simple things like weight loss; the scientific community does not altogether understand why people lose dramatic quantities of weight with Huntington's, but daily people need twice the food intake - two breakfasts, two lunches, two dinners. They need 7 000 calories or they just fade away to 20 or 30kg. Yet, as Viv says, they lose control of their muscles so they lose their ability to swallow, so they have to get twice as much food as we eat and yet they are choking. You have to keep the weight on or they are off their feet and are bedridden. So the quantities and complexity of care are enormous.

Mr WILKINSON - Where is it breaking down at the moment? There is obviously not the proper care available.

Ms ELLIOTT - Challenging behaviours are difficult to manage in any nursing home situation, especially, say, in aged care. You have frail aged, and you cannot really have someone younger who has some challenging behaviours, aggressive behaviours or whatever around frail aged people, so there is a breakdown there. It is a mismatch. In other situations such as Eskleigh they require more staff, more resources to care for someone in that situation.

Ms MARSHALL - And specifically trained staff, staff that are specifically trained in HD to manage that client and the package that goes with them.

Ms ELLIOTT - Yes.

Ms HAY - And at the moment they have that staff component who are trained in that way?

Ms MARSHALL - They are not always available.

Ms ELLIOTT - Traditionally they have had, because of the numbers.

Ms HAY - Yes, but not at the moment?

Ms MARSHALL - No.

Mr WILKINSON - With the staff at Eskleigh we were told that about eight or nine are on duty at the one time during the day, and around about three or four at night.

Ms ELLIOTT- Whereas a Huntington's person may require one on one.

Ms MARSHALL - Some, but not all of them. Some can fit into nursing homes quite easily and calmly.

Mr WILKINSON - Can I examine that a bit further? So the real problem is as with some of the clients who suffer brain injuries, where they are put in with the frail aged as well, but they obviously do not have the same needs, it would seem, as the Huntington's people. But is it a matter of numbers down here, that we do not have enough people suffering from Huntington's who need that assistance in order to have a special home set up for Huntington's people?

Ms ELLIOTT- That is debatable. The figure is 12 per 100 000. There was a prevalence study in 1990. I do not think we have done a lot since then, and the population has moved around a lot since then. There are families now that have come in from outside Australia and from other States to this State, so we have no idea really what the figures are. That is a separate issue. Our own service is under review at the moment, and hopefully some reliable statistics will come out of that. So it is really hard to tell how many people there are out there. The main issue is that in Huntington's old age is around 50. The Aged Care Assessment Team is the organisation that assesses a nursing home interest, they are not assessing people at the age of 50 or 55, so the avenue to any nursing home is cut off for our clients if they need it. That leaves the mental health system if they have challenging behaviours - not a mental illness remember, just challenging behaviours - so they can be housed with people who are simply not appropriate or they would endeavour to enter Eskleigh. As I said before, just recently there have been difficulties with that and that is both because there is a waiting list no doubt for Eskleigh, it is also about their funding, their level of staffing et cetera.

Mr WILKINSON - With your studies at the moment, how many people are actually being treated for the disease at the moment?

Ms MARSHALL - It is somewhere close to 100 people affected at any point but we can't give you a much more accurate figure than that.

Ms ABLITT - Some of these people are just beginning to show symptoms right through to people who are totally incapacitated.

Ms MARSHALL - And then you multiply that by something like five for the people at risk.

Mr FINCH - Are they dispersed around the State?

Ms MARSHALL - They are all around the State in the three districts - 64, 63, 62 are pretty even - but within that there are pockets where families have settled.

Mr WILKINSON - Can I just get back into that area, if you don't mind. We are looking at a figure of around about 100 at the moment that are being treated. How many do you believe at the moment need to be in a place such as Eskleigh?

Ms MARSHALL - Probably around about 20 or so and of those, probably less would need the sort of specific care. Some are able to fit into aged-care facilities.

Ms ELLIOTT - But that is not to say, even though they fit in, that aged care is meeting their needs.

Mr WHITELEY - That is the issue, I think. They probably could fit but is it appropriate is the issue.

Ms MARSHALL - You have someone of our age sitting beside 90-year-olds and singing Vera Lynn songs in singalongs.

Mr WHITELEY - Well, Jim does now.

CHAIR - Very badly.

Laughter.

Ms ELLIOTT - Just to broaden what you were saying, I would say in the north there are about three people who would really benefit from being out of other systems and into a specific care situation such as Eskleigh.

Ms MARSHALL - But we are really struggling to find them anything that works.

Coming back to your comment earlier about head injuries, I suspect that along with some other smallish groups, there is very clearly an opening in Tasmania for units to meet the needs of some of our people and some in other categories, but then we are back to this point that even if someone doesn't have particularly challenging behaviours, they even end up in a nursing home and I have had someone as young as 30 in a nursing home.

Ms ELLIOTT - To add to that, if they enter the mental health system as a stop gap, the only accommodation is in the south and this person may well live in the north-east, their family may be in the north-east; they could be far into the north-west and they would be accommodated in the south of the State.

Mr WILKINSON - What is your answer there?

Ms ELLIOTT - There are probably three issues. I think some type of additional complex care funding, something over and above the sort of funding that comes via Disability Services per bed, certainly a review of ACAT where the cut-off point is and 65 instead of 60 would make a difference to our clients. There are certainly people of that age group who do desire to go into aged care and whether or not they are receiving appropriate diversionary therapy et cetera, still they want to go there so I think they should have that option. And then a specific wing, ideally north and south. These people have been isolated from the beginning of the disease. Not only do they have to give up employment and driving, endure family breakdown, they are then in nursing homes and that cuts off contact with family. There is one loss after another.

Ms MARSHALL - Adding to that loss of value. We are not talking about a 90-year-old woman who is not able to see her 60-year-old son. We are talking about 30-year-old woman who is not able to see her 10-year-old child.

Ms ABLITT - And there are more and more of those younger people diagnosed today than there have been.

Mr WHITELEY - Wherever physically they are to be given a home, it will therefore be important that those surroundings are consistent with someone of that age. In other words, where children, husbands, sisters, brothers can come and feel comfortable. So what about the concept? Where there is a group situation, a bigger home, is that the thing - more specifically targeted services?

Ms ELLIOTT - Where relatives can stay, that concept, yes.

Mr WHITELEY - They can bunk down. If they have to travel from Smithton to Launceston, if that be it, or Smithton to Devonport, then they can stay the night.

Ms MARSHALL - I think it has to be two-pronged. It has got to have that specialist unit for people with these difficult behaviours where they do not fit elsewhere. The other thing is that wherever people may choose to go into aged care or whatever, that it attracts a bucket of money. At Scottsdale we have got a 40-year old who can employ someone to take them out shopping, to their children's concerts, take them to school and do all of those things that they do not necessarily have to do with 90-year olds. This 40-year old mum wants to see her children's school concerts, to go shopping and buy Christmas presents, so young people going into nursing homes need to attract a bucket of money, if you like, so we can meet some of their needs wherever they may end up being placed.

Ms ELLIOTT - You may be talking about an instance where a woman has symptoms ready for nursing home level and has a child of four or five.

Ms MARSHALL - One of the examples we gave you in here is a woman with three young children.

Mr WILKINSON - The answer is complex: one, funding; two, the ACAT cut-off age needs to be reduced; three, appropriate accommodation north, west and south.

Ms MARSHALL - Even just a unit. I feel that because of the age of these people they need to stay very close to home, so even if it is just two or three beds here and there rather than an Eskleigh that is going to take everybody with Huntington's.

Ms ABLITT - Yes, I would agree with that too, that you do not necessarily need all of these people in one place. God help the nursing staff.

Mr WILKINSON - But you need a specially trained nurses, don't you?

Ms MARSHALL - Yes, you do and we do a lot of that training and we are happy to help with that.

Mr WILKINSON - So therefore it is obvious an excess of funding is needed. If you have got two or three beds all around the State - and I can understand what you are saying so they can be near their families, relatives et cetera - but you need therefore added staff to cope with that, wouldn't you, because of the specialised needs that Huntington's would have?

Ms MARSHALL - A specialised nursing home has been tried in Victoria and to some degree in other states, but in Victoria there is a Huntington's nursing home. I went to visit that some years ago because it seemed to me like this would be wonderful. It would have dieticians who knew about weight loss and physios and doctors and everybody who understood and knew. Whilst it does have all of those skills, the clients go in one end and see what is going on. There is something to be said for the variety in a nursing home, where some people live a long time, some a short time and some are physically incapable and some mentally. The Arthur Preston centre which I thought was so terribly exciting has a downside.

Mr WILKINSON - So a two or three-bed system you believe would be a better system.

Ms MARSHALL - I suspect so. Clients at Eskleigh with a person who has Huntington's, and someone else with a head injury and so on. There is a mixing up of people

Mr MORRIS - As long as the mix is compatible, then mixing is fine.

Ms ABLITT - There are a lot of different neurological disorders. A lot of them have similar needs.

CHAIR - So you could be looking at specialised small facilities statewide taking people other than those who have Huntington's disease.

Ms MARSHALL - It may well be a younger person perhaps with a hip injury from a car accident or something who has challenging behaviour.

Could I add one more thing to the list? That is the importance of the current services that we provide in the community because they are under threat as well. I feel the specialised nature of the community service -

Mr WHITELEY - Could you elaborate on that?

Ms ABLITT - The Huntington services are funded by Mental Health and they have been under review for the last 12 months - officially. They have been talking about this review for so long it is not funny. In the last 12 months they have been interviewing people and talking to them and so forth. But yes, the services, I suppose, are under threat.

Mr MORRIS - Can I ask whether they are doing that review in order to develop a strategic plan? Is there a discussion paper? What is going to happen with the review? Is it going to produce a discussion paper and is that going to be available? Is the plan then to come to a strategic plan, whatever the outcome of it might be?

Ms MARSHALL - As public servants, I guess we feel a little bit awkward about answering that.

Mr MORRIS - Sorry. I just mean in terms of the physical process that is going on.

CHAIR - Joyce, perhaps that is your role.

Ms ABLITT - I am not going to get the sack for saying this. Mental Health is saying that they do not really see that Huntington's disease fits under Mental Health. It has come under Mental Health because of historical factors. Over the years this is where it has been and people like Professor Pridmore have been interested so therefore it has become -

Ms MARSHALL - Can I butt in, Joyce? I would add that the only pharmacological support for a person with Huntington's disease is psychiatric medication. It is really important because in some ways that emotional and behavioural stuff is what is so difficult for people coping with life and family life.

Ms ABLITT - But that is the only treatable part, so therefore you have to have access to the Mental Health area. Mental Health is trying to ascertain where Huntington's disease best fits. That was the aim of the review, as they told us. They talked to family members and to the association, of course. We represent families anyway. They have talked to people who are employed by themselves; they have also talked to a lot of people in other areas - to Disability Services and people like that. At the moment we are waiting on some sort of recommendations. Then we will look at that and respond.

I am probably sticking my neck out a little bit here, but it has become fairly clear to us as an association that Mental Health really would prefer the services to be managed by somebody else. What they have said is that another area of Health or to go into one of the non-government organisations. We are not entirely happy with the idea of it going anywhere else. The services, as they have grown over the years, have been excellent. They have always had wonderful staff. They are people who come in knowing nothing about Huntington's disease and they all go out, if they ever leave, as experts on the subject. It has been a wonderful service and we really would not like to see it change very much at all.

Mr WHITELEY - You mentioned earlier that this is a specialised field, how many professionals are there in the system who are skilled up at the moment?

Ms MARSHALL - Two-and-a-half is the short answer. There is a full-time worker in the south, a full-time worker between us two in the north and a half share -

Ms ABLITT - So we can say four people, but two and a half -

Mr WHITELEY - So that is the current status. To move to the magic wand area, it is going to require not just physical locations and a will to deliver that. It is going to actually require professional staff to support it.

Ms ELLIOTT - Oh, absolutely.

Mr WHITELEY - So what is the lead-up time period to actually take current professionals who may not be specialised and bring them into that loop? Does that make sense?

Ms ELLIOTT - Do you mean as far as sort of nursing home care is concerned?

Mr WHITELEY - Yes. If you were to move these people into more of a specific location as we have talked about, obviously, as Jim alluded to, it is a geographical decision.

Ms ABLITT - There might be some people already working with some of these people -

Mr WHITELEY - There won't be enough though, will there.

Ms ABLITT - No, but some of these people would be highly skilled, I would think, in working with Huntington's people because they have worked with them for a lot of years. They have also had training from the people -

Mr WHITELEY - I was not alluding to the fact that they are not skilled. I am asking, if the decision was made tomorrow and the whole thing changed, have we got the people, the professional nursing staff and whatever, to support that? It is not a three year thing or a four year thing?

Ms ABLITT - Oh, absolutely not.

Ms MARSHALL - If they have basic skills to work in a nursing home, then this is not a great leap forward.

Mr WHITELEY - That is what I was trying to get at.

Ms ELLIOTT - Part of our position description is that we visit nearly all nursing homes regularly and do information sessions and so on, so there are quite a lot of people out there who certainly have the basics.

CHAIR - And some of the people, I presume, like the physiotherapist who is already trained, just need a little bit of information perhaps about the specifics.

Ms ELLIOTT - And there is a bit of research now on Huntington's and physiotherapy. Certainly there is a little nucleus developing in the physio department at the LGH that has some understanding of that.

Ms MARSHALL - If I could get back to just adding to the list, if there is nursing home care, I guess I would ask that you keep an eye on what is happening with the review, so that the services that we currently have do not get eroded. In roundish figures, people have this disease for about 15 to 20 years. About the first 10 are in the community, and the last five are in care. They are very round figures - do not hold me exactly to them. The service and support of the community is just as critical, indeed more critical, to their quality of life to keep them at home and living well and happily.

Ms ABLITT - And some of these people are actually at home until they die. That is their choice and that of their family. That is a really, really hard job.

Ms RITCHIE - Can I just ask a question about the review? Obviously there is one under way. Have there been any previous reviews, or is this the first review?

Ms MARSHALL - Civil service started with the association trying to get workers. Until probably nine or 10 years ago it was just one part-time worker. There was not really much to review. It has sort of evolved and grown as the numbers have grown.

Mr FINCH - I have a few questions that may have been touched on before, but perhaps you could just clarify the circumstance for me. The Australian Huntington's Disease Association, Joyce, are you statewide?

Ms ABLITT - We are statewide.

Mr FINCH - From where? Are you based in Launceston? Do you have groups in each area?

Ms ABLITT - I actually live in the Burnie area, so our office is in Burnie, but we have a branch in Hobart, a branch in the north-east, a branch in Launceston and a branch in the north-west, and we each do our own fund-raising things and support work in those areas. We come together once every two months and have a meeting as a State body. So the branches are the fund-raising arms of the body, and the State body spends the money. We celebrated our 25th anniversary last year, so we have been here quite a long time.

Ms MARSHALL - It is very true that they are affiliated with the Australian body, which is affiliated with an international one.

Ms ABLITT - We have access to all of the information that comes from the international body on international research. We get copies of all of their papers or access to them if we want them.

Mr FINCH - Are you all volunteers?

Ms ABLITT - We are all volunteers.

Mr FINCH - What sort of funding do you receive?

Ms ABLITT - When we first got it, it was \$5 000 a year, and it has been indexed so it is a little bit more than that at the moment, but that is more than spent on our administration.

Mr FINCH - Okay. That centre you mentioned, was that the Arthur Preston Centre that you mentioned in Melbourne?

Ms MARSHALL - Yes.

Mr FINCH - Is that in Melbourne itself?

Ms MARSHALL - Its history, as I understand it, it was started by a guy called Eddie Chiu, a very highly regarded figure in Huntington circles worldwide - he is a neuropsychiatrist by trade with a particular interest in Huntington's, an absolutely wonderful man - and he

set up the Arthur Preston Centre with assistance because of the sorts of problems we are talking to you about of the difficulty of getting people placed.

It was in a tumble-down old building in a tumble-down area and it was highly inappropriate but it was warm and wonderful. Then, as sometimes happens with government funding, we have a new beaut single-bedroom, cold, awful upgrade.

Laughter.

Ms MARSHALL - You know what I mean. It has a wonderful history but it seems to have devolved in -

Mr FINCH - You mentioned the three people who are misplaced at this stage or probably not in an appropriate area, who actually takes on that challenge of overseeing their portfolio? Who actually just sees them through the system to try to get them into where it is appropriate for them?

Ms MARSHALL - We have a case management role.

Ms ELLIOTT - I can just touch perhaps on one person who has a State guardian so the guardian would make some decisions about what is happening to the person as far as accommodation was concerned. If they have family they would have input from the family but it probably would be our role to try to oversee what is happening.

Mr FINCH - What is available, what is best, where they should be, what is optimum?

Ms MARSHALL - That doesn't explain that you don't sit at meetings with Aged Care, Disability and Mental Health saying, 'No, no, no, and in the meantime do you want me to take them home with me?'

Ms ABLITT - And families of course have a role in this too.

Ms MARSHALL - We go up against a brick wall.

Mr FINCH - Yes, that is what I am really fleshing out here. Is that what you find, particularly with these three, that you just really can't make progress of you know they are not being dealt with appropriately by the system?

Ms MARSHALL - One person in recent times was pushed around like a football from bed to bed to bed.

Ms ELLIOTT - For one particular person it has been about nine months of being what I would call homeless, simply because they have been in acute care or district hospital care or mental health care and it has gone around in a circle. That situation may well be resolved shortly but it is my perception it is going to happen again -

Mr FINCH - Nine months is a long time when you talk about depression occurring with these people.

Ms MARSHALL - Especially if it is a person who is no longer on their feet, no longer able to talk, no longer able to swallow or relate well to other people - that in itself is an added trauma if you can't relate to people.

CHAIR - I am just conscious of the time so if there are significant points you would like to make.

Ms ELLIOTT - They have no idea what has happened to them or why it is happening and I don't mean because of the dementia - they just don't understand what is really going on. There has been no resolution, but there has certainly been a lot of discussion. All departments have done their level best to get together and talk about this situation but it is my belief if there were accommodation this situation would not have occurred. I would even hazard a guess that we are shortening this person's life by the trauma that they have gone through simply not knowing where they are living.

Mr BEST - What would be your guesstimate of what it would cost to care for an individual annually - just a rough guess?

Ms ELLIOTT - I am only talking about disability and it would be much the same cost as with many group homes, about \$60 000 or \$70 000 a year for one.

Mr BEST - That is a rough estimate. Obviously it varies depending upon -

CHAIR - Just being mindful of the time, final questions please.

Mr MORRIS - I am just trying to get a final handle on the numbers of people that we are dealing with on a statewide basis. You talked initially about having 12 per 100 000 which equates to about 60 for Tasmania but in fact we have got about 100 people now. Those are people with active symptoms as such. You are suggesting that roughly the first two-thirds of their 15 to 20 years would be still within the community and then for the last five, six years they would need some fairly intensive care. So that means that we have probably got in the order of 30 to 40 people -

Ms MARSHALL - Something of that order - 20 to 30 probably in nursing homes would be about right.

Ms ABLITT - I think Angela talked about 12 in the south.

Ms ELLIOTT - But, as I said, those figures are 1990 prevalence. Since then we have had a lot of movement, certainly families have come in, nationally.

Ms ABLITT - You are also getting second generations of families where the parent is still living, which is a little bit unusual and has not happened previously because people have died from it. But because of the level of care today people are living longer so you very often are dealing with two generations in the one family, which is a bit traumatic.

Mr MORRIS - The end point I am trying to get to is roughly how many people on an annual basis are coming into the system for whom we need to provide care? If we have 100 plus or minus, currently living who are showing active symptoms, is that about five or six per year, or between four and 10 a year?

Ms MARSHALL - We are looking a bit vague, but let me give you an example of something that actually happened to me. A lady walked through my door at work some years ago now and she had Huntington's. I could see that and I am not a doctor. She wanted to be tested and we tested her. It was unknown in her family because there had been early deaths in previous generations. The day we diagnosed her 128 people became 50 per cent at risk and then there were a whole lot more that were at 25 per cent so the demand on our genetic testing service just went through the roof. The demand suddenly on nursing home beds and all of that escalated. If we are looking a bit vague about giving you numbers, it is because it is a little difficult to do it.

Do we see a lot of new clients? I guess the short answer is no. Most of the families are known to us but I, in the testing service, would probably meet two or three a year of families that we did not know about; perhaps paternity has not been as it was thought to have been or whatever.

Mr WILKINSON - What State does it best?

Ms MARSHALL - Probably New South Wales or Victoria. The Australian president of the HDA at the moment is making very similar submissions to a very similar committee in New South Wales because they are having similar problems.

Mr WILKINSON - So New South Wales have got the same type of inquiry going at present?

Ms MARSHALL - Not quite the same, no, but she is looking to try to institute inquiries.

Ms ELLIOTT - Victoria has a man called Dr Eddie Chiu, who is -

Mr WHITELEY - What about internationally, is there any places in the world that are standing out?

Ms MARSHALL - Canada is very good.

Ms ABLITT - Places like Belgium and Holland have excellent care facilities. They do really good care stuff. Canada and United States are the areas where the big amounts of money are being spent on research, and also Britain.

CHAIR - Thank you. I do apologise for winding you up but I do have to stick to the timetable and thank you very much for your time. If we have any further queries or something comes up, I hope you do not mind if we get back in touch.

THE WITNESSES WITHDREW.

Mr DALE LUTTRELL, CHIEF EXECUTIVE OFFICER, ESKLEIGH FOUNDATION INC WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Ms Thorp) - Could we take this opportunity to look quite specifically at the terms of reference, and from your point of view, get your feelings and your position on the suitability of accommodation for younger people with acquired disabilities in Tasmania.

Mr LUTTRELL - Perhaps I will start with the history on this as to what Eskleigh does. It is a non-profit organisation which provides care for younger people. We have a larger group home at Perth with 42 clients and a number of other group homes throughout the State with smaller numbers of clients. Our greatest number is six. The majority of our clients, particularly at the home at Perth which you saw today, is clients with high levels of disability who require nursing services; some of them require constant nursing services. It is interesting to talk about the Huntington's disease clients because we have quite a number of them at the facility. That number is growing as far as we are concerned. We have a fairly significant expertise in caring for clients with Huntington's disease because it is specialised.

Generally, Eskleigh has the ability to provide care for clients with a varying level of disability, some with intellectual disabilities and some with physical disabilities at varying levels. The home, because of its nursing services, tends to take the clients with the higher level of disabilities than those who can live in the community or live in a group home. Bear in mind that we are the only facility in the northern part of the State and generally throughout the State that has 24-hour registered nursing services. From that point of view, from the accommodation point of view, the facility is always full. Because our funding is via Disability Services, we are required to use the Disability Services guidelines for filling vacancies and therefore a client who comes into our facility has to be registered as a Disability client. We then negotiate with Disability Services and assess the client.

Ms HAY - Can I just butt in? Did we hear earlier that Huntington's disease clients are actually registered in a mental health setting, not a disability setting? How, then, can they get into your facility?

Ms RITCHIE - They are now recognised by Disability Services.

Mr LUTTRELL - They are, yes. The bone of contention, and I am sure the Huntington's people spoke about, is that up until this year there was an issue that Huntington's disease clients were not registered as Disability Services clients because their disability was not defined as a disability under the Disability Services Act. Disability Services, after significant discussion, now accept that Huntington's disease is a -

CHAIR - It was treated like a medical condition?

Mr LUTTRELL - It was treated as a medical condition, yes. So Huntington's disease clients are now registered and can be registered with Disability Services, and can therefore take advantage of accommodation at Eskleigh. That is the situation. In fact this change in decision only occurred as a result of a change in Eskleigh's service agreement with

Disability Services. Up until 2003, Huntington's disease clients were regular respite clients and regular new clients at the Eskleigh Home. That is still the case. In fact we are taking care of a new Huntington's disease client in the near future.

CHAIR - Would it be fair to say by the time someone has come to you they would have had the disease for some time?

Mr LUTTRELL - Yes, the situation with the majority of Huntington's disease clients is that they will stay in the community or with families for as long as they possibly can. As the disability changes, and it changes quite rapidly - certainly the ones that we see change quite rapidly - then they will start to look at coming into a facility like Eskleigh. In fact a lot of the Huntington's disease families have always seen Eskleigh as the last part of their -

CHAIR - Because of the fact it is associated with family.

Mr LUTTRELL - That is exactly right, yes.

Ms HAY - When people have been living with family or friends for say 10 years and then their condition changes so they need to come in, do they actually apply to come into Eskleigh from that time? What would the waiting time be?

Mr LUTTRELL - The waiting times vary because the facility is always full. Clients who come into Eskleigh usually stay for the remainder of their life, so they pass away at Eskleigh. The only time we have a vacancy is normally if someone dies, so clients could be waiting for significant periods for a vacancy. We have had three vacancies in the last three months, which is unusual. Prior to that we did not have a vacancy for eight months, so clients would be waiting in the home or waiting at acute facilities, or on the street, for long periods of time.

CHAIR - And would it be fair to say, too, that during that waiting period there would be difficulties for the carers and for the client?

Mr LUTTRELL - There are difficulties for the families, because clients in the community have to access care via the Disability Services programs. These have to be individually applied for and funded through the system, so it creates enormous difficulties for the families. We have situations in our Community Care Program where clients without Huntington's disease, or disabilities that progress, need extra care but have to go through the Disability Services process in applying for extra funding, which is extremely difficult. There are very few funds around for extra care over what has been allocated. My understanding is that there is a significant waiting list within Disability Services of clients who require emergency care and emergency accommodation and who are waiting on funding assistance.

CHAIR - If you could wave a magic wand - Mr Wilkinson usually asks this question, but I will take it over - and create the situation in Tasmania that was ideal for younger people needing nursing home care, what would you create?

Mr LUTTRELL - In my view what is needed is different levels of group home accommodation. The best level of accommodation for clients is group home

accommodation, living together, groups that have similar levels of disability in small groups of between four and six. Eskleigh has a number of smaller group homes than the large home at Perth and the mix of between four and six clients seems to be the system that works appropriately.

A good situation is also providing care in the home but that brings with it enormous difficulties because our own homes are not normally designed for a person with a disability, particularly a disability that is progressive, and therefore you have difficulties with staff showering, toileting and all those issues that in a purpose-built facility are catered for are not catered for in the home. For instance, a client who may require mechanical lifting and because these machines are quite bulky, they will not fit into a normal bathroom or into a normal toilet so therefore whilst, from the family's point of view, care in the home is probably seen as the best option, it creates issues as far as providing a safe environment for staff is concerned.

Mr BEST - You have attendant care, residential care and nursing home facilities - they are the three. It would seem to me, just while we are at there, that you blend - they don't seem to be segregated or they are? I don't know.

Mr LUTTRELL - They are certainly not segregated. We don't like it being called a nursing home. I know it is called a nursing home in that brochure and that is something that we need to change - it is a home. It does say 'Eskleigh Nursing Home' but we have tried to change that over the years and we call it the Eskleigh Home now.

The way it works is that we group everybody together in a home environment, so we may have a situation where we have somebody with a severe intellectual disability in a room next door to somebody who has a severe physical disability and no intellectual disability at all. Past situations would say that that mix doesn't usually work. We have found that it has because we try to involve the clients in the decision-making process, we involve them in the care and we link together a client who has a physical disability and a client who has an intellectual disability, working together to achieve the best result.

Ms RITCHIE - Obviously there would be a degree of monitoring to see how the various combinations work.

Mr LUTTRELL - It changes all the time. As clients' conditions deteriorate or as their psyche changes then we will change. We will change with them and work with them. Where 42 people are living together there are always problems so the staff at Eskleigh are seeing client deterioration or changes and we work together as a management group or as a team together to say, 'Okay, perhaps it's time for this client to move to a different part of the home'. Luckily the way the home has been designed it allows us to do that without two clients fighting, for instance. One can be at the other end of the home so they do not actually see each other, and that works well.

Mr FINCH - We saw out there today that you have the single rooms and you have the shared rooms. What is the ratio? How many single rooms do you have out there and how many people need to share?

Mr LUTTRELL - There are five shared rooms.

Mr FINCH - So that is in the minority?

Mr LUTTRELL - Yes.

Mr FINCH - So generally people have single rooms?

Mr LUTTRELL - Yes. It is very difficult to have two people living together in the one room so that is certainly in the minority and we would like to see that change totally so that all of our facilities can be offered to clients on a private room basis.

Mr FINCH - Would you need to expand to do that? Could you do it within the present facilities?

Mr LUTTRELL - We could do it within the present number but obviously we would reduce our numbers. If we were to change that set-up then we would be looking at an extension. That is the longer-term plan of the foundations - to expand.

Mr FINCH - Let us talk about that a bit more. Do you have the opportunity there to expand or are you saying you do and you do not necessarily want to contain it to what it is now with just the 42 clients but you would be looking to perhaps have add-ons and doing more work there?

Mr LUTTRELL - Certainly the grounds at Eskleigh allow us to do a number of different things. We can extend the large home. The maximum we would want to extend that is up to 50 beds, or another 10 beds. Because we have nine hectares of ground at Eskleigh we have the ability to build independent facilities on the grounds, which could take advantage of the activities and the services that are available in the larger home but be in a smaller group-home environment.

In fact we have just, in the last 12 months, completed a six-bedroom group home on the site which was the original nurses quarters for the home. That is now a six-bedroom group home and that has worked particularly well because the clients are of a lower level of disability. They do not need a nursing sister all the time; they can take advantage of the activities that are offered in the home but if there is a medical problem with the client then it is only a matter of a registered nurse being on call pretty well straightaway.

Mr FINCH - That is not in your 42?

Mr LUTTRELL - No, we have 42 clients in the large home. There is another six there.

Mr FINCH - So where is the nursing home?

Mr LUTTRELL - At the top of the site, at the back.

Mr FINCH - Okay. And is that independent from your operation at the Eskleigh home?

Mr LUTTRELL - Yes. It is managed separately. We call that part of our group home set-up, so we have got that group home and a number of others throughout the State that provide the service.

Ms HAY - Whereabouts do your clients come from; just the north, north-west or north-east, and where do their family and visitors stay when they come to visit?

Mr LUTTRELL - They come from all over the State. There is no facilities for families to stay.

Ms HAY - Do they tell you, 'We are just in Launceston, give us a call', or do they stay overnight?

Mr LUTTRELL - No. Unfortunately very few of our residents have regular visitors. It is unfortunate but that is a fact. Those that visit regularly are those that live in the Longford, Perth, Launceston area. Clients that come from the north-west coast or Hobart very rarely see a family member. Whilst we try to offer them services - if we can we will have a client travel to their family in Hobart and all those sorts of things - it is all about money. It is cost and that is one thing that they cannot afford and we cannot afford to provide.

Mr WILKINSON - With this new proposal that you are thinking of, Dale, four to six-bedroom units, does that represent your belief about the best way to deal with it, to have a number of four to six-bed establishments around the State?

Mr LUTTRELL - Yes. There have been very few group homes built throughout the State in the last four or five years. Eskleigh itself has built two. We built the one at the home. We also built one in Hobart and we have bought land to build another one in Hobart, totally funded by Eskleigh on the basis of an investment. That is really the crux of it. We are looking at \$380 000 each and we rely then on Disability Services to provide us with clients with varying levels of funding to manage them.

Mr WILKINSON - So that four to six-bed group home, I suppose we would call it, that is the same as the acquired brain injury proposal as well. I know they were talking about having these group homes at one stage. Can the clientele that you have fit in with other clientele, let us say Brain Injury Association of Tasmania housing people with disabilities?

Mr LUTTRELL - That is how it works. In fact one of the group homes that we have in Hobart has clients who all have acquired brain injuries, non-motor vehicle accident acquired brain injuries, so they fit into that group and they have individual packages from the department and that seems to be the interest. When we purchased our most recent land, we advertised for clients who might be interested in moving into the environment that we were offering and our first plan was to build a four-bedroom group home, right next door to the one we had actually built in Hobart with a two-bedroom unit on the back. The feed-back that we received from the clients was that they would rather move into two-bedroom, unit-style accommodation that were linked so that they could share care. They all get a package of 34 hours a week care from Disability Services. That is not normally enough to provide care but if they were all linked together, living in a cluster, then they could share their care around so that you would have six levels of 34 hours a week at best scenario. That was the view that we took with this new development and that is that it is three two-bedroom units that are conjoined.

CHAIR - We only have about five minutes and I have questions from almost every member of the committee to go.

Ms HAY - How many staff does Eskleigh have for the 42 clients?

Mr LUTTRELL - There are 58 staff on the books. Full-time equivalent there would be probably 34.

Ms HAY - What sort of ratio is it then for say for the four to six group home or the three two-bedroom units? Is a lot more staff required in the smaller groupings?

Mr LUTTRELL - No, a lot more staff required at the larger home because -

Ms HAY - As per numbers though?

Mr LUTTRELL - Yes. In the four-bedroom group homes there is one staff member at a time.

Mr WHITELEY - And one can care for four?

Mr LUTTRELL - Yes.

Ms HAY - For six or four?

Mr LUTTRELL - At the six there is one and a half.

Mr WHITELEY - I was just going to pursue the issue of cluster: I was going to ask you how appropriate are clusters and you have basically said that seems to be the preferred way to fly. Rather than putting one in this suburb and one in that suburb with staff driving around in cars all day, you lean towards finding a place where they can have independent living but be linked?

Mr LUTTRELL - Yes.

Mr FINCH - Just on that subject: the ones that are in clusters, do they have a lower level of care?

Mr LUTTRELL - Yes. They certainly do not need nursing services. They would be supported by a support worker -

Mr WHITELEY - They have ISPs - independent support packages of 34 total hours a week?

Mr LUTTRELL - Maximum at the moment is 34 hours a week.

Mr WHITELEY - It would mean they are worth about \$100 000 each.

Mr WILKINSON - Which State does it the best?

Mr LUTTRELL - In all levels of care to people with a disability, whether it is acquired or intellectual, I think Tasmania is very high bearing in mind - and I am a bit biased here

because I was an ex-MAIB employee - that the MAIB started this process in 1981 with some enormous initiatives and that has developed a very good care system for economics of scale. I know the other States have got bigger facilities or more funds, but the background is very good in Tasmania.

Ms RITCHIE - I wanted to pick up on Kathryn's point in relation to families of clients and it is not unique to Eskleigh that there is not a large number of clients that do not come on a regular basis. Can you tell us what type of contact Eskleigh makes with the families in matters such as family satisfaction surveys, that sort of stuff - I think you do those, I know other organisations do - and what sort of feed-back do you get?

Mr LUTTRELL - We have a survey system that we run once a year. We have been doing it for the last three years and it is managed by an independent survey analysis organisation so it is dealt with independently so that the families see it as independent to Eskleigh and not as something that is -

Ms RITCHIE - Something that the others do as well.

Mr LUTTRELL - The last process that we did last year we had a 75 per cent return and an 83 per cent satisfaction of which we were very proud.

Mr FINCH - You talked about building that new facility and advertising for clientele, is that a commercial decision only or did you need to get a licensing circumstance to be able to take in a certain number of people who need support?

Mr LUTTRELL - No licence is required. It is a commercial and social decision. The Eskleigh board took the view after some fairly strong research that an enormous number of people were not being provided with adequate accommodation and care. At the time it had the financial ability to invest in these units, so it took a commercial decision to proceed with them the way that it has. There is no licensing required in Tasmania; however, we are required to be evaluated by the Health department's evaluation unit, and that is a process where the department comes in and assesses our quality of program and ensures that our clients are involved in decision-making processes and those sorts of issues. We also recently went through the ISO process for our quality program as well and, whilst there are no licences like there are in aged care, there is a general requirement to provide a service at a quality level.

Mr FINCH - Accredited.

Mr LUTTRELL - Not so much accredited but, yes, I suppose you could say accredited but at the quality level.

Mr FINCH - Were you assessed before you actually did the construction?

Mr LUTTRELL - No.

Mr FINCH - So you have established them, they are assessed and they suitably fits the requirements.

Mr LUTTRELL - Yes. When we did the construction we used Disability Services' design, and we used Disability Services' standards to ensure that bathrooms and bedrooms were the right size and wheelchair allowances were there. But it was a process of getting everything together and then making a final decision from there.

Mr MORRIS - What do you understand as the need in regard to people wanting access to, I guess, the group homes? We have talked about your having a waiting list of about 10 at the moment for Eskleigh - in that you could fill 10 more beds immediately if you had them. What about in your group homes? How many beds could you fill in group homes as such if you had the opportunity to build as many as you wanted? Where would you locate them and how many beds?

Mr LUTTRELL - First of all, group home accommodation is at a premium. My understanding is there are approximately 30 people requiring this type of accommodation statewide. I am not aware of the split of where that is, but emergency accommodation links to the funding.

Mr WHITELEY - Yes, and what is the driver?

Mr LUTTRELL - It is funds.

Mr WHITELEY - ISP?

Mr LUTTRELL - Yes. It is funds, and at the end of the day we could build three six-person homes easily, and we could probably find the clients, but then you have to provide the staffing.

Mr WHITELEY - That is where the ISP comes in. But as far as the ongoing operation and administrative costs, that would be funded out of their 83 per cent?

Mr LUTTRELL - That is it.

Mr MORRIS - Yes, I was just trying to get a handle on it. So basically you understand that 30 people could potentially move in tomorrow if the beds were there? Do you think there is a significant need beyond that of people whose actual need is for this type of facility but who do not have the processing places, who have not been through the system yet?

Mr LUTTRELL - It is untapped, because a lot of the clients, people with disabilities, remain in their homes in care by their family in situations that are not appropriate. So it is untapped, and I am sure we are dealing with an issue of hundreds. There are 100 people on the books at the moment. That is a particular disability. Where you have intellectual and physical disabilities these are not tapped. It is an enormous issue.

Mr BEST - I thought it was important for our record, the funding situation - 82 per cent of the pension and then you get topped up with the funding which comes from where?

Mr LUTTRELL - Our grants come from Disability Services. As an example, Eskleigh's budgeted income for 2004-05 is \$4.3 million and of that the majority comes from Disability Services; \$500 000 would come from clients -

Mr WHITELEY - From their 82 per cent?

Mr LUTTRELL - Yes, from their 82 per cent; the majority obviously comes from Disability Services and it is obviously labour based. Of the \$4.3 million, \$3.4 million, I think from memory, is wages.

Mr WHITELEY - How do Disability Services formulate their payment to you? Is it per person?

Mr LUTTRELL - I negotiate with Disability Services each year in relation to our past performance. Eskleigh, as a rule, makes a loss each year and we are not in the business to make profits each year but we need to cover our expenses. I negotiate with Disability Services each year in relation to what we expect our services to be, what we are going to get in and that is how we go. The starting point isn't based on beds -

Mr WHITELEY - It's not?

Mr LUTTRELL - No, however our service agreement has a client list attached to it.

Ms RITCHIE - Just adding on to that, I just want to get an idea about flexibility in these negotiations. If you negotiate with Disability Services and agree on a package for someone and then that particular client's needs change dramatically in, say, six months or 12 months, what is the flexibility to go back to the table and renegotiate? If you say the costs have gone up exponentially to service this person, what is the process there?

Mr LUTTRELL - We apply for client reassessment and Disability Services within their own services have client assessors and they will assess the client, assess the care needs and then it is a matter of reapplying for funding.

Ms RITCHIE - Is that something that can happen readily, though? Is that a long and arduous process?

Mr LUTTRELL - It is a very, very long process. The maximum, as I said earlier, is 34 hours a week and that is the maximum they will pay as a standard per client. If the client requires major extra care, and we have clients who do require that extra level of care, it is usually a ministerial decision taking up to three or four months. When I say 'three or four months to go through the process', it goes through the department, it goes through the assessment, it goes through the levels of agreement and then it is signed off by the minister.

Mr WILKINSON - The cost per patient, you say, is more than \$60 000 to \$70 000 a year and that was spoken about a short time ago.

Mr LUTTRELL - The cost of providing care is going up dramatically and obviously when you have a situation where clients are provided with care seven days a week and on Saturdays you are paying 50 per cent penalty and 100 per cent on Sundays it adds an enormous amount to the costs and with it you have issues of workers compensation, superannuation and all those situations so that the cost of providing care is going up dramatically. On average it would be \$70 000 a year per client.

CHAIR - Do you believe that there are young people with disabilities who are in inappropriate accommodation in Tasmania?

Mr LUTTRELL - Yes, there is a large number and they are accommodated in the home where the families are trying to look after them in inappropriate conditions or in aged-care facilities where they are, in essence, younger people in situations where they are with dementia clients and clients of old age.

Mr WHITELEY - Can I follow that up then. Could I suggest that there are people being withheld by their families or whatever at home because they say it is inappropriate. We would rather, as stressful as it and as hard as it can be, they say, 'No, we're not going to release them into these places because it's not fair'?

Mr LUTTRELL - Yes.

Mr WHITELEY - The need might not even still be quite appropriately known yet then.

Ms RITCHIE - I suppose that is a fear factor too because a lot of people still have the remnants of they go into New Norfolk and those sorts of things and they say, 'I'm not going to release my child or whatever into that'.

Mr LUTTRELL - I am sure that is the case.

CHAIR - Thank you very much and I hope, if we have further questions, we can come back to you.

Mr LUTTRELL - I am at Cressy any time. If you need anything, please, don't hesitate to give me a ring.

CHAIR - Thanks very much.

THE WITNESS WITHDREW.

LEO VINCENT LEYDEN, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Ms Thorp) - Welcome, Mr Leyden.

Mr LEYDEN - I am not really good at this. Could I read this out?

CHAIR - Absolutely, yes.

Mr LEYDEN - The housing of disabled people in group homes within the community has brought many benefits, however not all clients are best served by this approach as they need more secure environments and, in many cases, one-on-one care. This area seems to have been overlooked in an attempt to close down any residence which seems to have curtailed the freedom of people within.

Our personal experience is from living with and caring for a daughter who is now 47. With support from respite services, we are hoping to continue to do this but with each year more difficulties emerge. In the event of emergency, the death of or an accident to both parents, we have been told respite would step in until some form of accommodation could be arranged for our daughter. This of course puts extra demands on the services and limits the beds available to others. It would be good to know that some priority could be given to this area and the enclosed letter - and I will read it if you want me to -

CHAIR - You could table it.

Mr WILKINSON - That is priority for respite you are talking about, Mr Leyden?

Mr LEYDEN - Yes, our daughter needs complete -

Mr WILKINSON - Can I ask what problem your daughter has?

Mr LEYDEN - Sal was brain damaged at birth. She was a forceps birth and back 47 years ago things were not as good as they are nowadays and of course it was a lack of oxygen she suffered from there.

Mr WILKINSON - And you have been caring for her at home ever since?

Mr LEYDEN - Yes, for 47 years.

Mr WILKINSON - Have you had much respite?

Mr LEYDEN - We get respite.

Mr WILKINSON - How often do you get that?

Mr LEYDEN - When it is available. They are very good with Sally and she loves it up there but the trouble with the respite care is that there are so many others. I think Mr Whiteley brought up the matter a while ago that there are people who go into respite who have nowhere else to go and of course they take up beds for people who need respite and this

puts extra demands on the service and limits the beds available for others. If Sally runs away from home she will blindly cross an intersection. We live in Mowbray at on a couple of occasions she has gotten there. The police have been involved on several occasions.

Mr WILKINSON - Can you give us a bit of a picture of what it takes to look after somebody like Sally?

Mr LEYDEN - At home we have locks on all gates. A fence has been built at Rocherlea, at respite, to keep Sally in because she quite often runs away. She is one-on-one. She feeds herself. She has to be looked after as far as being showered is concerned and she is not toilet trained, as it were. When she goes to the toilet she has to be looked after.

Mr WILKINSON - So you have got to get up at night?

Mr LEYDEN - We used to a lot but now she seems to have got into a habit that she can go through a night now without any accidents or things like that. She can communicate in the family, with us. With other people she cannot. She has periods of time when she is very lovable.

Mr WILKINSON - Are there any other members of the family at all - brothers and sisters?

Mr LEYDEN - Three others.

Mr WILKINSON - And they all assist?

Mr LEYDEN - They are all away and married and have their own children now.

Mr WILKINSON - Did you find it difficult, during the family's upbringing having to divert the majority of your attention to Sally because of her problems and not being able to give as much attention as you would like to the others?

Mr LEYDEN - Not in the earlier months. Michael and Vanessa helped a lot but when Sally was about 22 or 23 she had this awful brain blow-up sort of thing.

Mr WILKINSON - So things became worse from 23 onwards?

Mr LEYDEN - Yes. She became more aggressive, if you like, and she developed a dislike, I think, of our youngest boy, Mathew. I think she became very jealous of him and to this day she still does not like it very much when he comes home.

Mr WILKINSON - Are there many support groups out there to help you? Obviously you and your wife would need those support groups from time to time.

Mr LEYDEN - She goes to the training centre at Rocherlea from about 9 till 3.

CHAIR - Is this part of a day service?

Mr LEYDEN - As a day service, yes, and we get respite times. We are caring for her now and we hope to be able to continue it. What we are looking for in this situation that we

have investigated and followed up for about eight years now is some where people like Sally can be in care and it is virtually one-on-one. These people are healthy and they are strong but they have not got the capacity to do things because they do not know how. As I said, one day Sally, is lovable and in an hour something will upset her and you have to sort of chide her and play with her and do silly baby things.

CHAIR - From your experience, Mr Leyden, would the facility at Eskleigh be appropriate for Sally?

Mr LEYDEN - It would not be because it would have to be a one-on-one situation. I listened with interest today. I had sort of investigated, without going out and talking to people about it, and that is a thing that we will probably have to look at. Our concern is Sally's concern - I suppose we're pretty selfish there.

CHAIR - No, no, not at all.

Mr WHITELEY - I don't think so, because we got your letter, which intriguingly is dated seven years ago, and I will try to get the words right so I do not offend you, because when you first started you talked about how you and your wife were prepared to care for her.

Mr LEYDEN - When our eldest boy was born, Sally was at that stage nice, lovable and cuddly and things like that, and then she deteriorated a bit. She used to go and get him out of his bassinette if we were not around and hold onto him and then drop him. Then when Vanessa came along we were a bit concerned. When Michael was born, and after she dropped him out of his cot on a couple of occasions, we took her down to New Norfolk and we were very unhappy about it. She was treated well, but not as well as you could treat her on your own.

Mr WHITELEY - But obviously 1997 is a fair bit past that time.

Mr LEYDEN - But I am just leading up to that. Then when Vanessa was about, Sally was becoming a bit more aggressive, so we decided to see if we could part with her for a while. But, anyhow, to cut a long story short we went down to New Norfolk with her, we went into the organisation and we turned around and came home again. But after that period we started looking hard for somewhere, because we knew - well, we are getting older and -

Mr WHITELEY - I think that is what I am alluding to. You have been caring for her brilliantly for 47 years - and, as you said, you are not getting any younger - and you are needing to find somewhere that you, as parents, feel comfortable with. I think you acknowledged what I was saying earlier about parents wanting to find the appropriate place rather than sending your 47-year-old daughter to sit with 90-year-old men and women.

Mr LEYDEN - Exactly.

Mr WHITELEY - So the issue for you is wanting to release her but into the appropriate environment.

Mr LEYDEN - Yes. And, as you made the point, there are people like that around. I am fortunate that I have been blessed with good health and I can do a bit.

CHAIR - I am sorry to have to cut you short, Mr Leyden. I do apologise. I am sure there is plenty more that we could talk about, but I am mindful of our other witnesses being present.

Mr MORRIS - How does Sally spend her days normally? What sort of things interest her? What does she do when she is not off at the day service?

Mr LEYDEN - To be quite truthful, she hangs over the front fence, and when the kids are at grammar school playing football or cricket she coaches them.

Laughter.

Mr WHITELEY - Do they win?

Mr LEYDEN - She hasn't had much success, I'm afraid. She stands out there all day and calls, and sometimes people go past and she's got quite a good vocabulary - I don't know where she got it from! I have also built her a swing down the backyard. She goes down there and she will sit on that for hours swinging backwards and forwards. She will join in with our grandchildren and laugh sometimes. She will run around with them and that sort of thing. We try to get her interested in watching the television if we can for a while but often the programs are not age appropriate - because she likes her ribbons and things like that - but if it makes her happy that is enough for me.

Mr FINCH - Do you constantly have to keep an eye on her? When she is outside have you got to be aware that she is still within the confines of the property?

Mr LEYDEN - We are continually backwards and forwards checking the gates because she took off one night. I came in, closed the gate up and didn't put the little lock on it -

Ms RITCHIE - It is like having a toddler with the strength of a 20-year-old.

Mr LEYDEN - Yes. I went back there and the next thing our friend was coming home from work and saw her going along the George Town Road by the Mowbray Hotel. This was at half-past-five one winter's night and with all the traffic. God knows how she got there. You have to be alert all the time.

CHAIR - Very impulsive.

Mr LEYDEN - Yes.

Mr FINCH - You were talking about respite and the fact that you get it sometimes when it is available, but often the beds are blocked and that sort of thing. How often would you get a break from what happens during the day? Do you look to, say, get away for holidays or just to get a week off or something like that?

Mr LEYDEN - We do, Kerry, but Dawn won't leave her.

Mr FINCH - Why?

Mr LEYDEN - Dawn will go across to her sister's place in Melbourne about three times a year but just stay there for two nights and that is it.

Mr FINCH - She wants to get back.

Mr LEYDEN - Yes, she won't let her go.

CHAIR - Thank you very much. We do appreciate it.

THE WITNESS WITHDREW.

DONALD MACDONALD, TASMANIAN ACQUIRED BRAIN INJURY SERVICE, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Ms Thorp) - Mr MacDonald, how would you like to proceed - would you like to speak to us and then perhaps we will have some questions?

Mr MacDONALD - Yes. If I could just mention, I am here representing myself as well as Allan Johnson from the Tasmanian Acquired Brain Injury Services. Allan couldn't come at the last moment because he was actually trying to find emergency accommodation for a gentleman with acquired brain injury and I will cover that in a moment to give you a picture of the problems related to that.

I will just talk about TABIS first and they have given me some notes which I have only read in the last 10 minutes or so.

Mr WILKINSON - TABIS being?

Mr MacDONALD - Tasmanian Acquired Brain Injury Services and that is a group that works out of Launceston. It covers out to St Helens way - a fair distance, I understand - but certainly out to Scottsdale.

CHAIR - Is that a document you want to read out or to table?

Mr MacDONALD - They have just given it to me so if I can have it at the moment because I want to make sure that I cover the points that they have given but I also want to cover a few myself.

I do work for TABIS. I have for about 10 years worked as a volunteer but in the last 12 months they have decided to give me some payment as well. I run what are called fitness therapy sessions down at Steve's Health and Fitness World which we do at various levels. From our point of view, it has always been provided totally free of charge, the fitness centre provides the facility free and we have four trainers who provide their time free. We have, on occasions, had assistance from physiotherapists. However, they require payment and we have had a couple of physiotherapists that have been very good and have provided guidance and that sort of thing over the years but that is where it stands at the moment, but if I just go back to TABIS. TABIS is an organisation that provides service to 105 individuals with acquired brain injury as well as 240 family members, the age group ranging from 16 to 65. They have addressed the terms of reference, I understand, so the first point was adequacy and suitability of existing accommodation arrangements, which I think Mr Luttrell was covering earlier, and the comment they have put in here is that they often see that the type of accommodation that is often offered is a group home facility, usually with people with an intellectual disability and that is totally inappropriate for someone with an acquired brain injury.

I think it is first of all important that you get a picture of somebody with an ABI and you think of yourself, after this meeting, leaving the building and having a brick fall on your head or being in a car accident or something like that and you wake up in three months' time or something like that and you have no memory of what happened but you still have

your nice long-term memory and you still remember you have a gorgeous husband, boyfriend, whatever at home, you have a girlfriend, a wife, whatever, but you are a totally different person when you get home because you are not the person that left that morning. You believe you are initially but you are not.

You are very moody. You have no short-term memory so you do not remember what you did five minutes ago or 10 minutes ago and you yourself have not really come to terms with that, because that is going to take you a long time to come to terms with, and your family certainly has not come to terms with that. Over the years in Launceston they have probably had very little information on who they are going to get home. They do not know until things happen. They suddenly start to realise the person does not remember anything short term. They suddenly find that they are not reliable. Outwardly often they look as they did before and if you have an elderly parent that you have tried to put in a nursing home and you have brought the people from the nursing home to do an assessment of them and suddenly they do not have dementia and they can put over a really good picture for the 10 minutes so that person says that they do not have dementia and the person goes away, writes a report and says, 'They are not ready to go into a nursing home.' You are ready to scream because you know that on a day-to-day basis everything is going wrong and often that is the situation with the acquired brain injury person and what is going on in the home.

They do not see themselves as having a disability. You would not see yourself as having a disability. You see yourself as you were before the accident. Not only do you not see yourself as having a disability but you want everything that you had before the accident. You want to turn up at work and you want to do the job that you were doing and you do not see why you cannot do it. You can go along to a panel interview. We have had them go along to apply for jobs and at the presentation they are fine; they can build up a story and they can present very well but when you put them on the job, they cannot do anything. I have one lad now who would most likely have been a doctor because it runs in the family and he certainly was academically gifted. He still sees that that is where he should be. He does not see anything else but you could not give him a job of labelling your books, and I mean the same label to go in each book because books will be missed and he will get confused and all this sort of thing but if you talk to him and you ask him what he wants to be, he wants to be something.

CHAIR - This kind of thing can happen with an aneurism, too.

Mr MacDONALD - Yes. I have two stroke people that were mentioned. Let us mention aneurism. We have Mrs Lee, who is a Chinese lady. She was the matriarch of the family, who ran a restaurant and that sort of thing, but she had a stroke. There is very little rehabilitation for somebody who has a stroke.

CHAIR - Should there be? Are you saying there is little you can do or there is little available.

Mr MacDONALD - There is little available. There is plenty that can be done but there is little available. Mrs Lee came to us in a wheelchair. She has lost language. She is very moody.

CHAIR - Has she lost all her language?

Mr MacDONALD - Yes, she has lost a lot of her Chinese as well. She has lost all English and much of her native language. Her daughter fortunately is doing some of the care but it was a situation there where the husband could not look after her. He had to work and the family found it very difficult so they put her into a nursing home. The problem is again that we have an acquired brain injury. She does not want to be in the nursing home so she started wandering. She started escaping. She is now in the dementia unit. Why is she in the dementia unit? She is in the dementia unit because she escapes. It is not appropriate but that is all we have got to offer.

If we go back to the gentlemen for whom we are trying to find accommodation at the moment, who is 44 years old, he was a construction worker, a very fit, healthy man who had his accident about 18 years ago. He is being cared for by his parents because he has never been willing to go into a home. He does not identify himself as having a disability even though in Paul's case he is in a wheelchair. He is in a wheelchair not because his muscles or his skeletal system will not support him, it is the nervous system that is the problem. He does not have balance so he is in a wheelchair. You have a person who does not identify themselves as being disabled, with the additional disability of the acquired brain injury which means he does not have the short-term memory. He is being cared for by his parents. He is 44 so as you can imagine his parents are getting on. He has all the social needs of the person that had the accident.

Think of how you are now. You were not born with the disability. If you were born intellectually disabled you would grow up with certain expectations and they would not be the same as your expectations are today.

Mr WHITELEY - Yes, you have taken on a social identity.

Mr MacDONALD - You have but the problem is all of a sudden all your friends are disappearing. They have a lot of things to cope with because some of them cannot just cope with the new personality that is there. They have lots of issues that they are trying to work through. So when you are thinking of putting them into accommodation, where are you going to put him? I have two 88-year-old parents whom I care for because they will not go into a nursing home. How in the hell are you going to get a 44-year-old man, who does not see himself as disabled and has all the needs of a 44-year old, into a home. You are going to ask him to go into a cluster home. The thing that concerned me about the cluster home was the mention that it was two bedrooms. Who are you going to get to share it? I do not have one acquired brain injury client - and I have quite a few and have had many over the last 12 years - who would live in the same room with someone else. We have enough trouble where we have them sharing a house with somebody who is looking out for them. These are people who have bought a home through the Motor Accidents Insurance Board, so they have been very lucky because they are compensable. But you have the added problem of a non-compensable.

Mr WILKINSON - And that is the real difference in this.

Mr MacDONALD - It is a difference but it still a problem with the compensable. We have enough problems with the compensable. When you throw in that they are non-compensable, you have so many other problems because a whole group of options has gone, ending with money.

My understanding when I spoke to Allan today as to what we were going to do with Paul, he really does not know because he has been refused entry to these homes. So it is not only a matter that we cannot get him in there. They do not want him. They do not want him because they see this inappropriate behaviour. He is an independent man. In a nursing home they have a curfew, they have a structure, and he does not want to live by that. Would you want to live by a nursing home structure tomorrow? That is what is being asked of these people, that they suddenly accept that. Why should they? It is a matter of coming up with an alternative, and they have not given me an alternative here, other than mentioning that there are some supported accommodations. I gather they are talking about maybe their own home or in a situation where they are living in a residence and have some support coming in. The cluster home - and I have not discussed this with Allan - where they are in an individual room may be different.

With the houses, I do not know how many carers Paul has gone through. They haven't actually been carers; the situation is that he has a lovely home in Elphin Road - two storeys - the last person was a mature-aged hairdresser. He had the whole top floor and it worked for a while. It did not work in the end because he still had someone living there and they did certain things that annoyed him and he does not have the ability to deal with those annoyances without it becoming a major issue. The marital home has broken down completely, and that is pretty well the way they all are.

I will run through a couple of other clients I have mentioned problems with. We have Rob at the moment. He had a stroke eight years ago and is now 55; he is caring for his elderly parents who are both ill. We have a young lad at Scottsdale who is 18 years old. He has had some physiotherapy. He had a bike accident and it is non-compensable because it was an off-road bike, but he has ended up with some physical injuries and an acquired brain injury. Because of the distance of Scottsdale he is not getting the physiotherapy that he requires. They have a physiotherapist out there and he has had physio for something like once a month. This lad should be walking now but is not. The problem is that because he has an acquired brain injury he is going to become dependent on that wheelchair. He needs to be out of the wheelchair as quickly as possible so that he gets walking. Not only is that going to assist in his normal mobility but it is also going to mean that later on he is not going to have a lot of the physical problems that you get as a result of sitting in a chair all or most of the time.

So why isn't he getting this physiotherapy when you think that we have lots of physiotherapists in Launceston? One problem is of course that parents have to organise transport. We have a community bus. The community bus doesn't want to take him. Why don't they want to take him? Because he has a wheelchair. It is not only because he has a wheelchair; he also has an acquired brain injury. It is not like the person in a wheelchair who gets on your bus and can talk to you normally and can relate to the passengers. You know that when you get to the other end all you have to do is get them out of the bus, into the wheelchair and they are off. So the community bus can't do all those other bits; I can understand their point of view.

So you have this lad stuck out there. The existing physiotherapist has gone into private practice, so they do not have a permanent physiotherapist any more and so he is not getting the physiotherapy that he was getting before. I suggested that the mother go to the LGH. The answer she gets from the LGH is, 'We don't like two physiotherapists

working with the same client'. She is a rural lady; she accepts it. She comes back to me and says, 'They said that', but can't physiotherapists talk to each other over the bloody telephone. I thought that was the thing with them, that they have this language that they crow about and anybody can't be a physio because we have this language that we use.

Mr WILKINSON - It would be the same treatment.

Mr MacDONALD - Of course it would give the same treatment, and the language is there. They can pick up the phone and in probably five words they can tell anybody to do it.

CHAIR - And what you are saying is that this lady accepted the treatment.

Mr MacDONALD - She accepted it, and that is a problem - the public accepts too much. If the public didn't accept what they are being given, your job and my job would be compounded because there are so many people sitting out there who aren't being rehabilitated properly.

The comment was made earlier, I think by Mr Luttrell, that the home situation was not appropriate on many occasions; well, often the home situation is appropriate if it is supported. The problem with the support was an issue of health and safety, as I remember. I am sorry but that is not acceptable. If there is a problem with health and safety in the home then that should be rectified by some sort of body coming in and giving assistance so it is rectified because probably the best place for them initially is -

CHAIR - You mean in terms of perhaps rebuilding the bathroom.

Mr MacDONALD - Ramps and rebuilding bathrooms and all this sort of thing because I gather that is what he was inferring.

Mr MORRIS - That's correct.

CHAIR - The bathroom was too small and that kind of thing.

Mr MacDONALD - So what do you do? Because the bathroom is too small we put them in a group home or something like that? Well, of course, the group home people say, 'That would be great', because they would fill it. We heard that there are 30 beds waiting. Well, I hope they are waiting for Paul because when they get Paul they are probably not going to be too impressed with what they get because he is certainly not going to be very obliging and easy to get on with. That is the character of acquired brain injury and it is not the fault of the person who has it. It is no different to the fact that they had a spinal injury and they couldn't walk or something like that. That is the way they are. They have a quick fuse. They have no memory, et cetera. Just to make sure I have covered what they wanted to say about access to other services, they wanted to mention the problems. I mentioned the problem with the hospital. Who knows what the physio was getting at, but on the day probably they had too much work on or something like that and they just did not want this problem, but this lad in particular is going to cost the community a hell of a lot more over his lifetime because he has been neglected now. It is within two years of his accident.

Mr BEST - Are there many people in this category who do not have any sort of financial cover because of the circumstance that there is no back-up? How do they come in contact with your organisation? Is it up to them to find you?

Mr MacDONALD - Often it is up to them. TABIS advertises and gets out there at meetings and talks about its availability. For a long time we had problems getting the hospital to actually refer people, but I understand they do now.

Mr WILKINSON - I know they do in the south of the State.

Mr MacDONALD - Yes. But that was a major issue, and there was quite a reluctance to do that. But there are referrals from hospitals, but that does not cover all those people who have gone before and who are sitting out there. I do not have a figure, because that is not the way our organisation works.

Mr BEST - I know, but would you imagine that there are -

Mr MacDONALD - I would imagine there are heaps. A lot of it is that you do not identify the person with the acquired brain injury because they present so well, and that is one of the real problems with providing a service for them. They do not see themselves as having a brain injury. They keep presenting themselves very well when they get out there, but they go home and they collapse. There is a young doctor who had the brain injury many years ago. Because he saved up all the frequent flyer points, we organised him a trip to Europe with a schoolfriend of his, a lass who had stood by him all these years. He always presented to her, even 11 years down the track, as the same person as before he had the accident. We kept telling her he is not. She and the family would get angry at us for trying to portray this lad as something different to what he presented himself as. She got him over there, waited till he had spent \$30 000 in mobile phone calls to his carer, to myself, to his trustees -

CHAIR - \$30 000?

Mr MacDONALD - \$30 000, okay. He has the money, because he is compensable. Nobody knew about that until he returned and the bills started flowing in, and you can imagine what his trustees did.

Mr WHITELEY - Took his phone off him.

Mr MacDONALD - But he would not remember having made the calls. He did not remember having made one five minutes earlier to me. He was distraught over there because his back-up system was not there. Okay? She was not coping because he was not the person that over those 11 years had presented himself as this stable -

CHAIR - It must have been an awful shock for her.

Mr MacDONALD - This was the problem. They were away for six weeks. When they came back it was six months before she could talk to him again. The family banned him from contacting her. He could not remember having ever done anything wrong. That is the sort of person you are dealing with. But we have had a lot of people out there who would not be as bad as he is in the disability area, who have had an acquired brain injury

at some level and who are not presenting badly but somebody along the track is suffering, or they themselves are suffering. We have one who I will mention who was in one of the homes I know in Launceston but he is not there, he has been missing for about five days. He has not returned home.

Mr WILKINSON - If I can, you have gone through a lot of the experiences that people have to put up with. I think somebody once explained it to me that if somebody has an injury you may as well go to a shopping centre and pick out anybody because they will come home a total stranger and that is what you seem to be explaining. What do you believe we as a committee should be doing and what recommendations do you think we should make?

Mr MacDONALD - I think something needs to be done regarding the rehabilitation side particularly for non-compensable cases. At the moment with stroke, ABI, spinal injury, there is the initial care and then there is the release. If they are compensable there is continuing care; if they are not compensable there is nothing. And the nothing is just not good enough because nothing then becomes an issue for the family. It is okay for the family that has the resources to care but even in those cases it is an additional stress. But for those that do not have the resources, somebody misses out - it might be other family members, or themselves. They will get older and they will not have the provision for their retirement and suddenly they are going to be in poverty.

Mr WILKINSON - That has been a big cry for a long time there that if you are an MAIB patient you are compensable but if you fall over and hit your head on the gutter on the way out of here today you are not compensable and you have problems. How can we overcome that? Money it seems to be, doesn't it?

Mr MacDONALD - Yes, but it needs to be in the health services - it needs somehow to be acknowledged that they need more rehabilitation. It is no good to say that they only need six weeks. Because of the way the hospitals are funded now, you cannot blame them - they need to have that patient gone.

Mr WHITELEY - So rehabilitation?

Mr MacDONALD - So rehabilitation. Accommodation is a problem. Also talking about mainly young people, there needs to be some social outlet for these kids because they do not have it. It is something we try to provide through the fitness centre. We do try to integrate them with other members of the centre, but they need to have somewhere. There is a problem with acquired brain injury because you are going to have inappropriate behaviour which is not something I have mentioned before. Often with them there is inappropriate behaviour because they have lost the barriers.

CHAIR - The inhibitions.

Mr MacDONALD - Yes, you have your thought but it never gets beyond that but with them it often goes the next two or three steps down the track. That is a problem but somehow we have got to come up with something for them to do because at the moment they will sit in front of the TV or they will get on the Internet.

Mr BEST - What are you saying is the solution in terms of accommodation?

Mr MacDONALD - I have not actually given a solution but what I have said is a nursing home is not a solution. Putting them with people with intellectual disabilities is not a solution because they do not have that. The assisted environment and the cluster home may be a possibility so long as they have their own space.

Mr WHITELEY - Independence?

Mr MacDONALD - Yes. I do not see them sharing the same building. If it is a separate building, yes, but the same building, no, I do not see it.

CHAIR - I am sorry, I am going to have to finish up. Is there anything you would like to leave with us that we can table?

Mr MacDONALD - I can leave you with all my little scrawls because that was actually given to me just in case I did not put it quite right.

CHAIR - Thank you very much. It was most appreciated.

THE WITNESS WITHDREW.

Mr GRAHAM PALMER, PARAQUAD TASMANIA, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIR (Ms Thorp) - Welcome, Mr Palmer.

Mr PALMER - Thank you for the opportunity. I am making this submission on behalf of myself and a Miss Penny Wattell who was hoping to be here today. She is an advocate and peer SUPPORT person with ParaQuad Tasmania. Much of the information I provide is anecdotal BUT I still believe it has some validity as it has been gained as a result of meeting and talking to people with spinal injuries, particularly those who have recently returned from the mainland after treatment.

Mr MORRIS - That treatment is mainly at the Austin Hospital, isn't it?

Mr PALMER - Austin and the Royal Talbot. There are no facilities here.

The main issues of concern - and I am a bit caught because Penny was going to help me with one of them - is the lack of availability of appropriate accommodation to suit the physical and psychological needs of the person with the injury; the lack of ongoing rehabilitation services - I did not know Don was going to be here today; he has stolen a lot of my thunder - and difficulties of accessing sufficient appropriate carer hours to facilitate an independent life and reintegration with the community.

Mr BEST - We heard a few minutes ago about this accommodation matter and it was suggested that perhaps some sort of cluster home - I know that was a different issue because when we are talking about some with brain injury it is very different to physical injury. Do you see that as a possible solution?

Mr PALMER - No. I think people with spinal injuries, even those with very high dependency - I will quote one example: when you have a lesion in your cervical region where it can be almost to the point where you are numb from the waist down - it is possible for those sorts of people to live an independently as possible in an individual unit, with a huge amount of care. I am not privy to the exact costs so unfortunately I cannot quote them. It has been given to me that the person, even with those really high dependency needs, can be accommodated less expensively than being, for example, in aged care facility, which is often the place they tend to end up. I can stand and walk short distances and anybody going from my level and beyond can still be accommodated independently.

Mr BEST - That is because obviously you are able to be independent. You can organise things.

Mr PALMER - Yes, your brain works. If you have some mobility in your upper body then there is nothing preventing you from having a fairly normal life. Even if it gets to a higher level, with help those people can still live normally. There is a huge amount of technology which can help those people.

It has already been emphasised the difference between those who are compensable and non-compensable. Our presentation is predominantly based on the issues affecting people who have non-compensable injuries.

Mr BEST - Are you aware of many people ending up in inappropriate care because they are not getting that support that you are talking about in regards to independent -

Mr PALMER - It is very difficult to say. I have got some statistics to say there is over 150 people under the age of 65 in Tasmania with profound disabilities but there is no break-up as to what they are. Over the years, and we are talking as some people have already mentioned, some 30, 40 years where people have had these disabilities, as to when they might have been placed in that care no-one will know and I have no idea of where you go to find out who would know.

Mr BEST - It is possible though that someone could end up in an aged-care facility but it is unlikely insofar -

Mr PALMER - We do not know. I will save that for later but there is only one instance and from the statistics that I was able to get, it looks like there are only three people under the age of 30-something in aged care at the moment.

Mr WILKINSON - One of the problems with respite is, isn't it, that you get a lot of younger people put into aged care for respite and it is long term?

Mr PALMER - That could be so, yes, and although I was involved and have been going along to a meeting through Julian Edes from the organisation which covers the whole range of disabilities, I have tried to focus my presentation on the issues relating to people with spinal injuries.

Mr BEST - Obviously you would consider that inappropriate in those cases that you are aware of?

Mr PALMER - Yes. I believe there is one person here in Launceston who is living in Cosgrove who is quite happy to do so. I do not know his age but he is certainly not an elderly person but he has been offered other options and he is quite happy, so there are horses for courses.

I have some statistics on spinal injuries which I will not go through because you can follow them up but, just broadly, each year in Australia between 300 and 400 new incidents of spinal cord injuries, or SCIs, are added to the existing population of around 12 800 cases. The incident rate was, in 2001-02, 12.2 cases per million population which roughly equates, if my maths is correct, to six new cases each year in Tasmania. It is difficult when you fiddle around with statistics like that but Penny who sees a lot of these people when they do come back to Tasmania feels that that would be about right. Of course she does not see the ones that go to Hobart.

The breakdown may be of interest. Predominantly a large number of these people were inside motor vehicles when they had the accident or outside motor vehicles and hit by them or on motorcycles, cyclists or pedestrians. Unfortunately the statistics which were provided by a researcher from the Flinders University do not, strangely enough, give an

actual break-up. I thought I had the statistics but when it came to breaking that down, I could not.

I think since time is probably of the essence, I will let you read that in your own time. Summarising, it would be fair to say that approximately 80 per cent of the cases are either covered by compulsory third party motor accident insurance or some form of work cover and the remainder may be settled through some sort of legal action but we never know about that.

When it comes to Tasmania, we are talking about perhaps one or two cases per year of non-compensable patients which is why we, in our organisation, are concerned as to why the Government would make it so hard or make a differentiation between those that are covered by insurance and those that are not. They seem to go to great lengths to make it as difficult as possible for those who are non-compensable to access the services, the equipment and whatever they need. If you do not know what is available, who to ask, where to ask, what you are entitled to, then in most of the cases we have come across, unless you are a very assertive and sometimes aggressive person you will not get anything. If you are meek and mild and sit there, you will just sit there.

Mr MORRIS - We are about to meet one who knows exactly what she wants.

Mr PALMER - I think I know who you mean.

CHAIR - Oh, of course, click!

Laughter.

Mr WILKINSON - Those one or two people you say who acquire these disabilities who are compensable, are you talking just spinal -

Mr PALMER - Spinal, yes. I have touched on other disabilities, but my focus is really on the spinal side of it. It could be medically acquired, and that covers things like MS and a whole range of neurological conditions as well. Accommodation has been pretty well covered. As I say, due to the Privacy Act it is not possible to establish how many people fall into these categories and are affected by the lack of any of these services and, most of all, accommodation. But it is my understanding that there is a thing called the Spinal Account which is administered through the LGH where certainly a large number of these people would be known because they deal with these people and the only way that they can access money is by applying to the Spinal Account to get a wheelchair or equipment. I even think - and I stand to be corrected - that when they come back from treatment in Melbourne, that account also has to cover major things such as home renovation and all that sort of thing. I think it is a very modest sum. I will not quote figures because I do not know, but when someone like that comes along it really blows a hole in the budget. I guess that is something that perhaps this committee could look into.

It is a fact that Advocacy Tasmania was able to establish that there have been no group homes built in Launceston for any people with profound disabilities in the last six years, except for those relocating out of institutional care. I am afraid I cannot elaborate on that any further, unless anyone else has already done so. Young people, as the person you are waiting to speak to later on will attest, either wait in hospital wards for non-existent

alternative accommodation, or settle for a place in some other institutional facility which might not be suitable to their needs. Despite this, the very statistics that I have quoted, there is an increasing number of people with spinal cord injuries, and it calculates out to be an increase of about 3.3 per cent per annum, and this is unlikely to recede in the short term. Each year the State Government delays in taking action to address this unmet need and allocate funds for the inevitable new cases, the situation can only worsen. Add to this scenario the fact that medical improvements enable more spinal cord-injured patients to survive the initial trauma, and this will inevitably mean they will require long-term support for a much longer time. Spinal cord patients are now more likely to live longer and will probably reach a normal life expectancy or not much short of it, increasing the demand for services into old age.

While the issue of spinal cord patients living in aged care does not appear to be an issue, I will just illustrate a point where people can slip through the cracks, and it is a tragic case, and although it is old news I think it still serves to make a point. This one particular person was very high-dependency and was placed in an aged-care facility - Cosgrove, I think it was - and remained there for 18 years. It was only the intervention of an advocate from AQA Victoria, who were then involved in Tasmania, that resulted in him being moved out, but it took several years for that to happen and only the good work of this particular person, who was himself a quadriplegic and an advocate, enabled this person to get out of the home.

I will mention the circumstances he was in. He was in a room that was too small to manoeuvre a wheelchair. He left it only to shower. He would sit for several hours in the company of people with advanced senile dementia. He had no control over the balance of his finances after the 80 per cent or whatever it is - I think it is 83 per cent now - of his pension was paid and the other items of expenditure were just managed by the staff.

The process to convince the department took several years. Eventually in 1991, assisted by his advocate, he was moved into a purpose-built unit. To enable that to happen, the person who helped him had to agree to go along and occupy the other unit, which he gladly accepted for himself but also to enable this person to get out of the home. The savings to the Government, compared to a full-time, aged-care combination is calculated to be \$30 000 a year.

Don has stolen a lot of my thunder and I didn't know he was going to be here today. Since the dismantling of the State Rehab Service in 1997 there has been little access to ongoing rehab for those with non-compensable injuries. I am not sure what it is like for people under MAIB but they have access to paid physios and a whole range of services, I would imagine. This once provided a full range of services to all Tasmanians with disabilities. Rehab now exists in name only in the north, although Royal Hobart provides one small ward which is generally only available to people when things have reached a point where medical intervention is necessary rather than providing preventive measures. I have been there on a couple of occasions myself and it is only a small ward in that hospital.

The following comments are also anecdotal but they are based on actual experiences of spinal patients from the time they arrive back in Launceston after being discharged from the Austin or the Royal Talbot. From this point on rehab is in short supply at best and at worst is non-existent. Physiotherapy is rationed due to staff shortages or policy

decisions, and patients who should be getting a continuation of treatment are left without rehabilitation while such matters as remodelling their home or availability of care is arranged.

Access by the patient to a gym or even the physiotherapy department itself may be restricted on the grounds that one-on-one supervision is deemed necessary and that there is insufficient staff to permit this. This, in the opinion of my doctor who is involved in the hospital in this area, is not or cannot be substantiated. There are many people with spinal injuries who could access the equipment and the facilities and who would benefit from it. I believe this is due to a degree of paranoia on the part of the hospital management, who fear, like a lot of other people, potential litigation in their duty of care are loath to allow anybody to have access to equipment which is sitting in a room that stands empty most of the time.

CHAIR - Mr Palmer, please excuse me, but I am mindful of the time. There is a lot of information here which we will be able to read. I am sure that there are specific points you would like to make.

Mr PALMER - I have made a selection of points about my own case. I find it very hard to accept that there is no rehabilitation. I quote examples of people who have gone along to Don's facility at the gym where remarkable changes are made when the effort is put in. I guess from the Government's point of view, when the money is spent. There are some good outcomes; people can retrieve some function, which often is small but significant to them and if they continue to get rehabilitation could even progress further. Until Christopher Reeve does his job and gets us all up walking, then most people are going to remain in much the same condition they started in but it can make a difference to many people who are given the opportunity of rehabilitation. It makes them feel better and in my case it impacts with pain because of spasticity, which affects a lot of people with paraplegia and quadriplegia. I am going to Sydney on Saturday to receive treatment because it is not available here.

Mr WILKINSON - That is a physiotherapy-type treatment is it?

Mr PALMER - It could be. It is for pain management and that sort of thing.

Mr WILKINSON - I suppose if you do get some improvement it is hope, isn't it?

Mr PALMER - Yes. I do not know whether it is the same now because other governments in other States may have had to make the same cutbacks. It was quite a different scenario there, where treatment was regarded as essential and worthwhile.

Mr WILKINSON - Was your paraplegia caused as a result of a car accident?

Mr PALMER - No, mine was a work-related accident. After about five years we had an out-of-court settlement for a very modest amount, but it has helped.

Mr WILKINSON - That settlement would have included ongoing medical assistance?

Mr PALMER - No, it didn't. It would not have done any good here. It was a lump-sum payment but the Government still provided the facilities for ongoing rehabilitation every

week and going in annually to have a 'lube and tune up' - a week to 10 days of intensive physiotherapy to bring you back up to a reasonable standard.

Mr WILKINSON - Are you saying from this that that does not happen?

Mr PALMER - In Tasmania?

Mr WILKINSON - Yes.

Mr PALMER - There is no such thing in Tasmania. I can be as categorical as that: there is no such thing as rehabilitation in Tasmania.

Mr WILKINSON - Some would argue that in the south the Douglas Parker Rehabilitation Centre used to give you that.

Mr PALMER - That is right, but that closed about three months after I arrived.

CHAIRMAN - But you came down believing that facility would be there?

Mr PALMER - I made stringent inquiries as to the availability of services and I was told that there were and they would accommodate my requirements.

Mr BEST - On the rehabilitation, how involved is it?

Mr PALMER - Having dismantled the structure, to put it back together again would cost huge amounts of money. If someone did a cost-benefit analysis, if there was such a thing, as to what it was giving back as opposed to what it was costing, they just look at the cost side, not the benefit side. I go back to the WA situation. I had a friend who was in rehabilitation when I initially had the accident. He had motor neurone disease and he received rehabilitation up until about two weeks before he died. They did not stop that and say, 'What's the point?'. That would be the case here: 'What the hell's the point of giving rehabilitation to someone with motor neurone disease?' - as in stretches or other physiotherapy. He benefited from that physically and mentally. Someone here in Tasmania could benefit from receiving rehabilitation treatment on an ongoing basis. It has been proven. That Mrs Lee, the reason she gets up and walks out of houses is because Don got her up walking. She was in a wheelchair. She was great while she was in a wheelchair, a quiet little patient. 'Sit there and do what you are told'. As soon as she could walk, she was out so it creates some problems, but they are good problems.

Ms HAY - In regard to the treatment you are going to Sydney for on Saturday, is that available in most other States around Australia?

Mr PALMER - Yes, it is. I went to a very comprehensive, world-renowned pain clinic in Western Australia. I cannot answer for the other States. I know Dr Slatyer runs the rehab. He is probably pulling his hair out trying to figure out what he does with his budget. It is just quick-fix stuff. It is not ongoing, strategic or preventative. It is fixing the thing up after the thing broke.

Ms HAY - This Dr Slatyer, are we seeing him? Can we do that?

CHAIR - We can invite him, yes.

Mr WILKINSON - Where is the place in New South Wales.

Mr PALMER - I am going to speak to the pain management centre at Royal North Shore Hospital.

Mr FINCH - How will you finance that, Graham?

Mr PALMER - It cost me \$149 dollars to go on Jetstar to Sydney and back. It costs me \$60 in petrol to go to Hobart plus a night's stop in a motel. It is cheap and it is a world-class place. I have not made inquiries but I do not believe that there is any way that there would be the same facilities in Tasmania. It is a two-day comprehensive review, going through everything and then they decide what they are going to do, for which I might have to go back. There is nothing in Tasmania that will come anywhere near that.

Mr FINCH - Did Dr Thatcher arrange that for you?

Mr PALMER - No. The only other neurologist in private practice in Hobart has just moved to New Zealand, Dr Bruce Taylor, who was my registrar in Perth but I have not seen him in 10 years. He has now moved so it only leaves one neurologist in Launceston and one at the Royal Hobart who is probably climbing over a case load of people you could not jump over.

CHAIR - Thank you very much for your time and all the very best.

THE WITNESS WITHDREW.

Mr ALLAN STEPHENSON WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

CHAIRPERSON - Thank you very much. We do apologise for keeping you waiting but as you have been here you probably understand the process we are using. If you have any documents you would like to share with us, we can always copy them.

Mr STEPHENSON - You probably all have a copy of the document that I have written out. I did not really know what I was in for today - this is the first one of these that I have been to - so I just jotted down some points that were relevant. I realise there are not a lot of points that are relevant to a lot other people but I can only rely on what I knew -

Mr FINCH - That is good.

Mr STEPHENSON - for the first one I will use my particular case. I spent a year in Melbourne undergoing rehab that could have been done in Tasmania. After the accident I went to Melbourne; I was unconscious for approximately three weeks. I was in ICU for a month and after that I think that I could have come back to Tasmania. I spoke to one of the doctors at the LGH and he said to me, 'We haven't the expertise that they have over there' which is absolute rubbish. The people are just as qualified as the people over there.

Most of the rehab that I was going through - stretches and learning how to do them - was being done by 18 or 19-year-old girls who were actually training at the university. Surely, we could have 18-year-old girls or guys here doing exactly the same thing. So that point that he made that you had to go to Melbourne - for the spinal surgery, yes, but I was in Melbourne for one full year and when I arrived home - my wife was devastated by the accident - I found my marriage falling to pieces. I was home for three days and had to go back -

Mr FINCH - Allan, was it the Austin Hospital?

Mr STEPHENSON - I went to the Austin for five-and-a-half months and then to the Royal Talbot for four-and-a-half months.

Mr FINCH - Was it a car accident, if you don't mind my asking?

Mr STEPHENSON - I was riding a quad bike at the Carrick Speedway. Some people said, 'Come out for a ride' but we should never have been there. A quad bike is not meant for that sort of thing.

Mr FINCH - I am just wondering about the circumstance where you have gone to the Austin Hospital whether case histories show that they need to keep people there to view their progress and they have the people with the skills to oversee your circumstance.

Mr STEPHENSON - I see what you are saying but when you are lying there in the bed and you see what is happening, you realise that the same thing could be done here in Launceston. One of the things that they say is that spinal patients have a fairly poor

chance of surviving marriage after the accident. My spending a year in Melbourne was like the divorce had already started. I think I would have had a much better chance if I had been here in Launceston. In the 12 months I was away I saw my children twice, which was very hard to deal with, and it would have been a lot easier if I could have seen my children on a regular basis. Not only does it help them emotionally, it helps you as well. I went through quite a bit of trouble - there were so many new faces, people who I didn't know and couldn't relate to - but if you are there with your own wife and kids it would have been a lot easier.

Mr FINCH - Is there any financial support for your family to go over to Melbourne?

Mr STEPHENSON - No, that is another point. There have to be empty seats on planes going across. Even if they said to the wife or the husband or daughter, 'We'll give you four hours' notice at the very most and see what we can do. There might be a plane on Sunday afternoon at 4.30 if you want to go to Melbourne and see your dad or your mum or whatever'. If the plane is going across with an empty seat why not put someone's bum on the seat and send them across.

Mr WHITELEY - We are not talking about huge numbers, are we.

Mr STEPHENSON - No, we're not.

Mr WHITELEY - Maybe five patients from Tassie?

Mr STEPHENSON - That was another thing. I think that somebody actually mentioned to me the numbers of people so I sat down one day and I counted them. There were 20 people on the ward and five of them were from Tasmania. That is a quarter of the population of the ward.

CHAIR - And you are saying, in your opinion, that would provide the critical mass to provide that service back here. There's enough people needing the service?

Mr STEPHENSON - Yes. We have some reasonably good spinal doctors here and it is only a plane flight from here to Melbourne or from Melbourne to here. The spinal guy who looked after me, Andrew Nunn, comes across regularly and checks up on me to make sure that I am doing okay, so why couldn't they send over a doctor to check on everybody once a week.

Mr MORRIS - Once you have passed the acute stage then you could easily be back here and receiving the support and the rehab here, being close to your family.

Mr STEPHENSON - That is right. It would make you feel better. You are talking to people that you know and if you feel better, you are going to get better.

Mr FINCH - Just to reinforce a point you made there, I am just thinking back in my memory, probably about two years ago a friend of mine had to have an gynaecological operation - I am just not sure what it was, I knew it involved a cancer - she went to the hospital in Hobart and a team of four flew in from Melbourne and operated on her in Hobart and flew back so that was an interesting circumstance. That is what you are saying, is it not?

Mr STEPHENSON - That is exactly right. As far as I know there is a lot of documentation that I have not been able to get my hands on - they do not work too well now anyway; just finding information for me is very hard - relating to what help have we in Tasmania for my wife and children to come across and see me. I do not know if there was any but I think that in the long run, especially when a marriage falls to pieces, if we could help the family before that happened it would be a saving all round for everybody, including the taxpayer - if we can keep that family all together by organising for them to see each other or get that person rehabilitated here.

Mr FINCH - It might be something that the airlines could do in cooperation with the State Government - are you suggesting something like that? If we do have people who have to go away like you did for 12 months, that there could be some support from the airlines through the State Government?

Mr WILKINSON - Years ago that used to happen. Ansett used to do it.

Mr WHITELEY - Times have changed, of course. The landscape has changed.

Mr STEPHENSON - Yes. If they knew that a 9 a.m. flight on Monday had 10 empty seats and there were two people going they could be accommodated. The seats are empty; the airline has lost that money anyway.

Mr MORRIS - The Government could buy those seats very cheaply, I am sure. Potentially that would not be difficult, would it?

Mr FINCH - Airlines used to be very sympathetic right through the community, not just to accident people, but we do not have that level of cooperation now or support back to the community.

Mr STEPHENSON - It would be a completely different matter if someone high up in the airline lived in Tasmania and had the same problem that I have been through.

CHAIR - You mention in point 5 that when you returned to Tasmania after that year in Melbourne the level of rehabilitation care that you received was inadequate.

Mr STEPHENSON - The amount of rehab in Launceston General Hospital is non-existent. It is absolutely disgusting. If that is what they call rehabilitation, somebody in charge wants to go and have a quick look in a dictionary to find what rehabilitation is. I have better equipment in my lounge room which I purchased myself and which cost me \$15 000. There are two bits of gear that could keep you going for quite some time. I have better gear in my house than the Government-funded hospital has, and it is looking after thousands of people. Why is that? I have spoken to them and the people at the LGH have been out to my place and actually looked at the gear.

Don MacDonald that was here earlier, he looks after me - I have got to pay for that spot twice a week to get my stretch done. Don has looked at my gear. I said, 'Don, if you get somebody you think needs this gear I will lend it to you; you can check this person out or bring them out to my house and see whether it can be used'. Then they can see first hand this is definitely a piece of stuff that we need and they can go and buy one. It is

expensive - expensive for me at \$15 000. I sat down in the kitchen for hours thinking, 'Will I or won't I?' Then I thought, 'I have had enough of this. I am going to go and do something for myself'. No-one comes and pushes you and says, 'We want you to go to rehab'. I would like to be an asset to the State but I am not at the moment; I am a liability. People are paying for me to get things done. I want to get back to work.

Mr FINCH - Where did you get the stuff from, Al?

Mr STEPHENSON - I bought it through a place in Sydney.

Mr FINCH - And how did you know about it?

Mr STEPHENSON - It was exactly the same gear we used at Royal Talbot.

Mr WILKINSON - How did you know about it?

Mr STEPHENSON - It was exactly the same gear we used at Royal Derwent. That is how I knew it was good, and I knew that was the stuff that has been bought. You can get your wheelchair into it, so you could do your arms and all sorts of upper ones which are the muscles that I need to push myself. It is a U-shaped thing and you sit in your own chair so you do not have to do a transfer. The weights can be slid backwards and forwards - just push a lever and slide it. Every night just before we get into bed I would have to go to the toilet, and you make sure you are empty before you get into bed. Because you have been sitting down you get fluid in the legs, and once you lay them out flat in bed you can be in an hour after you go to bed you are busting to go to the toilet. I am lucky that I have that feeling. I do not have control of it, but I have the feeling, so I suppose that is one good thing. But when I get on this bike, which is an electric bike, it will stop if you have a spasm. You put your legs in and strap them in, and I can sit there and watch TV and just peddle away. It tells me to do 15 minutes, but I have to do more than that.

CHAIR - And that gets rid of the fluid retention?

Mr STEPHENSON - Yes, because it is actually moving the muscles, so it is a good thing, but it was \$5 500. What do you do? You need it. At that stage I had some money so I spent it on good stuff.

Mr FINCH - Were you covered by insurance?

Mr STEPHENSON - No.

CHAIR - I am very intrigued by the points you make about the Child Support Agency, because the Child Support Agency in my understanding is a Federal body and you would think that their treatment would be consistent from State to State.

Mr STEPHENSON - Never open a can of worms. The Child Support Agency do not - and I would stand to be corrected - see quadriplegia. The Child Support Agency worked out my child support on the wage I was earning prior to the accident, and I asked 'How did you do that?' Actually they said the year before I arrived home. I said, 'In that case I don't have to pay any, because last year I was in hospital'. Then they said the year

before. I said, 'Who is going to wash the dishes, wash my clothes, clean the house?' I was trying to undo a bottle of sauce and it slipped and smashed. I couldn't wheel around in the kitchen. It was all up the curtains et cetera. I had to ring the guy from up the street to come down, and he and his wife pulled my kitchen to pieces and washed it. You have to pay people. Everything that you do around your homes, I have the pleasure of paying people to do the same.

Ms RITCHIE - But the confusion seems to be, from reading point 7, that you are suggesting that New South Wales recognises something that Tasmania does not, and how can that be if it is a Commonwealth system? That is what we are trying to find out.

Mr STEPHENSON - You will have to excuse me because I don't know. I actually kept the clip and showed it to the CSA. It stated in the *Examiner* that the New South Wales Government had conducted some sort of inquiry and found out that it was a certain percentage higher for paras and quads to live.

Ms RITCHIE - Right, but they are not providing any financial benefit. They have just said to the Commonwealth, 'Hey, you need to look at this'.

Mr STEPHENSON - Yes.

Ms RITCHIE - That is what you are saying.

Mr STEPHENSON - Yes.

Ms RITCHIE - Okay.

Mr STEPHENSON - They brought out something and said, 'This is what we have worked out that it costs'.

Ms RITCHIE - I understand what you are saying now. Okay. I was just clarifying that.

CHAIR - So basically what you are saying is that the amount you have to pay for child support for your family, when that formula was worked out it did not take into account the fact that because you have quadriplegia means that you have additional costs that you have to bear?

Mr STEPHENSON - They kept sending me out forms to fill in, and I do not have much chance. My three-year-old daughter could write better than I can. I cannot push a biro. I have to use a felt pen so that I can drag it. It is a bit cold today so my hands are a bit clamped up. I had numerous run-ins with them in a year to try to get them to send somebody out. I said, 'I cannot get out to the office. I do not have a vehicle, and the carer hours are only 30 hours a week and we are over that now. How do I get out? Is there a wheelchair-accessible toilet? Can I get in and out?' I said, 'Send someone out so you can see for yourself what you are dealing with'. I kept ringing up the number on the bottom of the form and the guy I spoke to was in Mooney Ponds. I did not know that. He said, 'There are 6 000 people who need to see someone and you've got no hope'. I thought I was dealing with someone in Launceston or Hobart. They finally sent someone out. The girls who came out are only there to fill out the forms for me.

CHAIR - They are not there to advocate on your behalf.

Mr STEPHENSON - No. They are very cold; they are not interested. I have said to them, 'Can you give me somebody's name to whom I can speak?' and they said no. I said, 'You can't or you won't?', and they said, 'There is no-one'. I said, 'Who is your boss?' 'I have some paperwork here to leave for you'. I am on the computer and I can tap away on one finger.

I have just written a letter and sent it to a lot of parliamentarians and headed it, 'To those who are prepared to listen'. I cannot get a captive audience to sit down and listen. There are problems, would you please listen to me and at least look into them. I went into the antidiscrimination tribunal and I said to them, 'I am being discriminated against on these grounds'. They said, 'Oh no, you aren't'. It was one government department talking to the other and I got nowhere; they were not interested. Child support - I have no faith in them whatsoever. Things that I have asked them to look into have not been looked into. Information, when it has been sent back off their computer is as if you deleted half the conversation this afternoon. That is what was being sent back. I would go back and write down points of interest to them but not all the points that were brought up.

Mr FINCH - Allan, you might have it explained here but I haven't come across it. How are you accommodated at the moment? Are you in your own home?

Mr STEPHENSON - I was lucky that I owned my home prior to the accident; I owned my own business as well. Straight after the accident the business had to be sold. I have some income protection which is paying my wage. While I was in hospital my wife did not pay any tax. I did not know this and it was eight months or so after I arrived home that I realised no tax was being payed. Even with the child support, if I start paying it now, if there is any money to come back, I am going to lose it. I am trying to hold back until such time as I can get it sorted out. I think I am up for three years of probably \$5 000 each, so there is \$15 000, and then there is child support which is another \$5 000.

My wheelchair has broken or the tiles in my kitchen. The sharp edge has punctured the tyres. The new kitchen was built over the old tiles and I have been quoted \$6 000 and \$9 000 to rectify that. I am not sure who paid for this but the wife sent the builders away when I first arrived home to have the house made wheelchair accessible. I have had to pull one door off to get in and out of the kitchen. I cannot get in and out of the walk-in wardrobe, so if I have an accident I cannot get in to get any of my clothes. I cannot get around the back of the house. I do not have the full bill yet, but the labour bill was \$4 500 to fix the fences. I will get some of that back when I go to the council. I cannot get around the back. I have been told by Commonwealth Rehabilitation Services to get a vehicle and get out, see people, go out, do things and get out of the house. The vehicle was going to cost approximately \$20 000. That is being organised. Then it has got to have the hand controls but for me to be able to get in and out of the car myself, I need another wheelchair so there is another \$6 000, and besides that I have child support. Every time that Child Support comes back to me and asks me something, I have got to either go to the doctor, to the lawyer and get it in writing - which is fine; I have no problem there - but child support was about to be sent there at one stage and the case support officer said, 'I've just phoned your wife. I'm sorry, we're going to have to put it up as your wife has two children going to a tutor, one to two times a week'. I ask, what

is one to two? It is either 50 per cent more or less. The argument there is that if we have all got to supply written information we all need to supply written information.

Mr WILKINSON - Child support is governed on the moneys that you receive though, not on the needs of the other side. That is how they do it. Years ago it used to be on the needs of the other side but now it is on a percentage of your wage and the number of children that you have and they work out the formula from there. Are you seeing a solicitor about that?

Mr STEPHENSON - I gave solicitors up because I cannot afford that. People keep saying, 'Go and see a lawyer'. How? With the bills I have now I have no hope of doing that. I paid the wife out around about \$230 000 all up, plus the money that she had taken out of the bank before she left. She has bought a new house and a new car. The boyfriend has moved in on \$80 000 a year. They have a total income of over \$100 000 and I have to pay into the little nest to help them out.

Mr WILKINSON - How old are the kids?

Mr STEPHENSON - My eldest daughter is 14. My son has just turned 13. My youngest daughter is 9. My wife now has a silent number. I went to the girl in the court and I did the wrong thing. I took a tape recorder in and I taped it to show the lawyer. The lawyer was not interested. She said that is illegal. I said to the girl, 'Where are my rights as a father? Why can't I still see the kids?' She categorically said to me, 'You have no rights'. I thought that was disgusting.

Mr MORRIS - It is not right. That is not correct; you do have rights.

Mr STEPHENSON - So as far as the kids go, I cannot phone her. She has a mobile phone now. If I want to ring I have to use that. That is conveniently turned off. If I do want to and spend five minutes with each child, which is not a long phone call for a kid, I am up for a dollar a minute - \$15 - just to say, 'Hello. How are you?' I understand it is hard for her to come into the street and see all the old neighbours but now the kids are getting to stay away from dad. It is the same as if they said, 'Mum, we are not going to school'. You would say, 'Get your backside in the car. You are going'. I just expect that a father could get to see his kids but I have no contact. Nothing.

CHAIR - Bringing ourselves back to the terms of reference which include, as you know, the suitability and appropriateness of accommodation, alternative options and particularly under point 2, rehabilitation, if you had a magic wand and you could fix things in Tasmania overnight, what would you like to see?

Mr STEPHENSON - As far as accommodation is concerned?

CHAIR - Yes, and services to people in the position you are in.

Mr STEPHENSON - We will just take a number out of the air; we will say that there are 10 people. That is today. Tomorrow there could be 20. If we need five houses, you would need to build 10. That is just to start with. If you do not use them for a spinal cord injury or acquired brain injury people you could put short-term people in there until you can find accommodation. We need some accommodation, unless they come up with

a miracle cure. Let us hope they do but until they do, we need somewhere to put people; some for short term, some for long term. I do not see anything at this point in time.

Mr FINCH - Would you see yourself using accommodation like that, Allan?

Mr STEPHENSON - Yes. I wanted my wife and children to stay in the house, because I was in hospital still, and the only place they could find for me to go was Eskleigh or something, and the spino said, 'There is no way I am going to let you go there'. He said, 'Your house has been changed, and you must go home', so I went home to an empty house, which I found extremely hard. My house is on a bit of a hill and I cannot get around the back at all. I have to be very, very careful. Yes, I may need to go somewhere when I get older, but at this point in time I am okay.

CHAIR - So specific accommodation is a real need. Would you like to summarise your thoughts on the rehabilitation situation?

Mr STEPHENSON - As far as rehabilitation is concerned, I have not seen rehabilitation in this State. I have not seen anything that I could say is rehabilitation. There is nothing, and that is absolutely disgusting. As I said before, the gear in my loungeroom is better than the gear in the rehabilitation centre at Launceston General Hospital. I have had to use a piece of gear that is home-made. It is weights on a pulley that you pull down to strengthen your arms, and the thing is that worn out on the pulleys that they are seizing up on the shafts. They are that worn I said to the guy, 'Go and lubricate them'. He said, 'We've got no oil'. There is just no gear there. I have a standing frame which would leave the one in the LGH for dead.

Mr FINCH - Is this in their physiotherapy department?

Mr STEPHENSON - Rehab, physio.

CHAIR - Are there any specific questions that any of you would like to ask Mr Stephenson while we have him here, a captive audience, so to speak?

Mr MORRIS - I think we have been given far more information than I was expecting that we would receive, and the quality of it has been fantastic, but I think what it shows up is that we have a long way to go in this State.

CHAIR - Thank you very much. We do appreciate it, Mr Stephenson.

THE WITNESS WITHDREW.