

THE PARLIAMENTARY STANDING COMMITTEE OF COMMUNITY DEVELOPMENT MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART ON TUESDAY 19 OCTOBER 2004.

INQUIRY INTO YOUNG PEOPLE WITH DISABILITIES IN NURSING HOMES

SUE HODGSON, HOPES; **DEBORAH BYRNE**, BIA; AND **MARY LANGDON**, TASCARE, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

Mr DEPUTY CHAIRMAN (Mr Finch) - Thanks for your attendance today and thanks for the submissions that you have sent to the committee already. You are all here really under the same umbrella, aren't you? Would that be right?

Mrs HODGSON - More or less. Perhaps I could explain. We are very closely interlinked and we all are looking at similar problems but Deborah works for and represents the Brain Injury Association of Tasmania and she has another hat on in being member of HOPES. I represent HOPES but I am also the mother of a person with an acquired brain injury and Mary represents Tascare Society for children but also is on HOPES.

We are interlocked with similar issues to discuss.

Mr DEPUTY CHAIRMAN - Okay. And you, I would imagine, have great hope that our committee can get some results for you. Would you like to speak individually first up?

Mrs HODGSON - That is fine. I have already put in two submissions; one a personal one and one on behalf of HOPES, so I will not go over that too much. If there are questions that people want to ask, that will be good.

I have put an additional sheet of paper on the table in front of you because from my perspective there are historical issues. I guess one of the frustrating things for me is that my daughter actually sustained a brain injury at Christmas 1985 and following that I was very much involved in trying to get things happening because I think until you are directly involved you do not actually realise that there are not any services out there.

I am just going through on this sheet what has happened since 1986 because I do not think it was covered necessarily in the submission. At the time my daughter was in the Royal, there were five young adults with acquired brain injury, all with severe outcomes. Two of those people had been there for two years, simply because there was nowhere for them to go.

The other issue was that at that time when people completed acute care at the Royal, they were discharged to home, nursing home, or some place found for them and then, in theory, had access to the Douglas Parker Rehabilitation Centre. However, there were

issues surrounding that. You could only access Douglas Parker if you had a reliable yes/no answer. My daughter had been in a coma for three months, and for three months following that the only recognition we had was a thumb up for yes, so she was classified as not having an adequate, reliable yes/no answer.

You also had to be continent, but at that stage she was incontinent, and finally you had to be compliant. In my daughter's case that was not such an issue but for many people with brain injury it is because of the nature of their cognitive disabilities. We did not have access to rehabilitation as such.

Jackie was discharged home to us, against the wishes of the doctor, who wanted to put her in a nursing home. Subsequently we worked with other people to start our own support group which was Headway Support Services.

Without going through each year in turn, by 1989 a group of us had an audience with Robin Gray and I think he was a little bit surprised. We took a delegation of people with acquired brain injury and their families and he commissioned a State report, which was done. Following that, he commissioned Chris Cuff from New South Wales to do a report on brain injury in the State.

At that stage we started getting quite excited that there was some progress being made. I guess this is why I am so frustrated because then, in 1990-91, things started to turn around and that was very much to do with partnership arrangements between Motor Accidents Insurance Board and the then State Government. It was a non-party-political thing in that we started off with Robin Gray in the Liberal government but then, when Michael Field came in, it continued on and Michael Field was the Premier who officially launched the Tasmanian brain injury program.

I guess at that time we were quite positive about the future. We knew it was going to be a long-term process but we had believed that there was now a rehabilitation centre and subsequently an in-patient unit built on what was the old school at the back of Douglas Parker Centre. I do not know if any of you saw that at any stage but for the four years that it was up and running it was a state of the art unit which cost a lot of money. It was very well presented and was a non-hospital setting, for want of a better term, so that people with acquired disabilities, both spinal cord injury and acquired brain injury, could go there, following acute care, for their rehabilitation. It also had enclosed courtyard areas so people who were wandering or had cognitive problems were able to get outside and families could visit and it was a really first step in the transitional process.

The next stages from that were to be transitional living, moving, into long-term accommodation. Motor Accidents Insurance Board, because of their future care legislation, were then responsible for their claimants and as a result of that they initially purchased property at Otago Bay, subsequently sold that and built the property which you may or may not have seen at Montrose. They built another property in Launceston and they contracted Eskleigh to manage those two properties. That management has now transferred to Anglicare and Eskleigh has built a group home down here of their own.

The issue for both groups, both government and MAIB at that time, was that because of the small population there really needed to be a viable mass to make things work. The

intention was that there would be one emergency acute care unit that specialised in brain injury, which would be here at the Royal Hobart Hospital, and then there would be an in-patient unit based at Douglas Parker Centre and then people would return to their region for tertiary, or whatever you like to call it, rehabilitation and long-term accommodation. However, lots of problems erupted, one of which was a parochial attitude of Tasmanians. Launceston did not want their patients to come to Hobart. Families did not want their family member to be in Hobart; they wanted to do things in their own region, which meant immediately that the numbers became very small if we were to specialise.

The other issues that impacted at that stage were a switch towards economic rationalism and more pressure put on Motor Accidents Insurance Board to concentrate on its core business, and a change of management. All these things worked together to rethink and relook at what was currently happening. So the initial thing that happened was that the in-patient's unit became watered down. It was originally a 24-bed unit: 12 for acquired brain injury and 12 for spinal cord injury. That became watered down to allow anyone with private healthcare cover to come in. Ladies with hip replacements and strokes, not only women but particularly elderly ladies. That meant there was no longer any justification to train people to specialise in acquired brain injury. So, as you can imagine, it all became somewhat watered down. Ultimately, after four years the unit was closed. If anybody has been there recently it is now office space for the Catholic education system, which to me was really sad because if you had seen the way it was set up originally and the money that went into it, it was a little bit devastating.

On top of that of course the other thing that was put on hold was any transitional or long-term accommodation planning. I guess that has been my concern now; after 10 to 12 years we seem to have gone almost a full circle. I am sure the others, Deborah in particular, will tell you that we currently have people sitting in the Royal who have been there many months longer than they should have been because there is no place for them. Possibly the slight change in that time is that families are not so prepared to let their family member go from the hospital to a nursing home. So because of that they are saying no to the nursing home options. What is then happening is that the department is under stress and duress to find some emergency or crisis response to that situation, which in many cases is not working. There are examples of people who have been moved out of the Royal where the accommodation and support has proved to be inappropriate. So they have then been moved onto somewhere else at vast expense and this money means that it has not been available to the wider disability population. I have met with two families still stuck in the Royal with nowhere to go and I believe there may be as many as six people waiting at the moment to move out of there.

So from my point of view I am just frustrated. Four years ago now, Jim ran a hypothetical for HOPES to look at these issues and once again we received these positive feelings about how everybody felt that there needed to be something done and something planned, but four years later we are still fighting the same battles. I am very happy to answer questions later but I will not take up more of the time. I think as far as the HOPES information goes, you have it there in the submission. Allison has been very helpful to us in the past too, and Tim. So I will not go over the HOPES issues at the moment if that is all right.

DEPUTY CHAIR - Thanks very much, Sue.

Ms HAY - Can I just say I really respect you coming to say today that you appreciate us taking the time, but at the same time you have gone through this before and we have gone the full circle and we do really hope we can do something. I do not think there is a member here who just wants it to be another 15 years and you coming back again and being frustrated. So thanks for specifying that point; it made a lot a sense to me.

Ms HODGSON - If it is necessary to come back in 15 years I just hope I am still there to do it.

Laughter.

Mr WILKINSON - Sue, what do think is achievable?

Ms HODGSON - In a nutshell, my concern is and we will all say the same thing, I think - is that there is no planning. There is no long-term plan and as a result a lot of money is being wasted on crisis response. My feeling is that when I went back to see what had happened over the years, it worked for us initially, in my opinion, because we had Treasury directly involved, so that Treasury and MAIB and the Government were sitting together to look at the issues. One problem we seem to be having at the moment is that we are working with Disability Services and trying to work with the minister but the answer, of course, all along the line is, 'Well, we don't have the money from Treasury and it appears that there's money for crisis response because you can pull that from wherever, but not in terms of an actual Budget allocation, and that is what is really needed.

DEPUTY CHAIR What we might do is just hear the other submissions first and then we will ask questions then.

Ms BYRNE - As Sue said, I have been with the Brain Injury Association of Tasmania for two years and I am also a board member on Brain Injury Australia. We both prepared, I guess, to come and talk independently and both took the view that we had given you quite a bit of information that looked at the historical stuff. Of concern, as for Sue, to the Brain Injury Association are the notes that I made that there was an accommodation working party formed back in 1993 to look at accommodation options for adults with a range of disabilities. I thought it was interesting that some of you have just recently done that same thing again, looked at the statistics and also sought possible funding options. That was back in 1993 and that looked at the issues that we raised, the fact that for many people who have acquired brain injuries that fall into that non-compensible basket, the age for the injury occurring is usually that 16 to 30-year age group. They are younger adults with a normal lifespan. Previously, their living arrangements were either living independently in a rented home or sharing with a person, perhaps buying their own home or in family environment, or were preparing to move out on their own. They actually end up moving, as a result of their brain injury, to a dependent situation for the post-injury care which, as Sue said, is being cared for in the family home, being supported by a partner or being supported in a share house for that age care facility.

As I said, the issues back in 1993 identified what some of the nursing home issues were, which was that overwhelmingly elderly environment, the contradiction of normalisation principles, the lack of supported funds for the younger needs, the limited interaction with peers, the elderly activities, the limited opportunities for community integration and the

loss of friends. They were the concerns back in 1993. In addition, in Queensland there was a report done in 2001; there was a young people in nursing homes summit done in 2002, there was a big conference last year attended by 450 delegates, plus all the other young people in nursing home alliance activities. At the State level in October 2002, you are probably aware that the disability services put together a young-people-in-nursing-homes project proposal which was to scope and review the status of younger Tasmanians with disabilities currently in Commonwealth-funded aged care facilities and also to identify potential service models for supporting younger people with a disability who also have high medical and nursing needs in the community.

There was a progress report done on that in February 2003, which, if you have a look at, basically said nothing. It was just reiterating what the project will do. In December 2003 we all gave up a day of our time across Tasmania to attend a community forum with an outcome of a report that summarises the issues and potential models for Tasmania. I am sure you all have that information and we can all do that.

I guess for us, the icing on the cake was the disability services third-draft strategic plan. We are currently waiting for the final version of that. Point 2.3.2 says that they were going to convene a statewide working group to discuss and develop service options for younger people with disabilities in nursing homes.

Mr MORRIS - Doesn't that sound like we're going around in circles.

Ms BYRNE - It was, and it was interesting that Sue was going around in circles from 1986 when she first started, and then ten years down the track, so we are still going around and around in circles.

Mr STURGES - Disheartening. Let's be honest.

Ms BYRNE - Yes, it is disheartening, as was that lack of understanding by the minister at the time. There was a letter that Sue and I both worked on that went to the editor in response to the minister. He talked about appropriate rehabilitation services being provided in hospital, but the research shows that once a patient is stable, a hospital environment is not appropriate for rehabilitation. He stated that the preference, where possible, is to support the patient to return to live with their relatives, but as I said previously, the majority of these people were living independently. They were not living with relatives and for most young people there is an expectation that they will move out of home and live an independent life. It also talked about a nursing home bed being used as an option, especially in more remote areas. These were areas in which we had a concern about lack of understanding by the minister, which we all continually come up against. It also goes to, I guess, the other hat that we wear which is the unmet needs campaign and that lack of forward planning.

The other issue that I noticed I did not actually include in the submission is one that the Alliance of Young People in nursing Homes has been talking about. The Brain Injury Association is actually in the process of developing a very comprehensive report about acquired brain injury in Tasmania and that will be circulated to everyone. We are just waiting on statistics and information on disability services. Traditionally, disability services has, I guess, acted on an intellectual disability model. There is a very poor lack

of understanding and awareness within disability services and the general community itself on acquired brain injury and the differing issues there.

Mr WHITELEY - So they actually tend to put them in one bigger bucket, inappropriately, a good intention but -

Ms BYRNE - Yes, and treat people -

Mr DEPUTY CHAIRMAN - Whose doing that report, did you say?

Ms BYRNE - The Brain Injury Association is currently developing a report on acquired brain injury that looks at the issues of population and has some recommendations. You would probably be aware that quite often you get groups talking to you about what the issues are, but I think it is having a look at some of the recommendations, what is actually needed, the main one being is that need for forward planning.

The other issue is that need for the no-fault insurance scheme. One of the biggest problems that we have within the State and across Australia is the compensable versus non-compensable, so if you are lucky enough to have a brain injury where you have compensation then a lot of your medical expenses and rehabilitation is covered, but if you are non-compensable then -

Mr MORRIS - Just make sure the car is insured before you crash.

Ms BYRNE - Yes, insured, registered et cetera and that you are not at fault.

Mrs HODGSON - I understand Treasury and Disability Services are involved in looking at that issue nationally and internationally at the moment; they have had some meetings.

Mr MORRIS - Are they? That's interesting. I virtually have another reference, which is precisely that for this committee. I am just holding off on it at the moment.

Mrs HODGSON - The name we were given in Treasury was Chris Locke, so if you contact him you might know what it is all about.

Ms BYRNE - Looking back at other notes that I had from a meeting that was held with the minister, once again it just illustrates a part of the problem. The comments at the meeting were generally disappointing as the minister continually reiterated the current lack of funds and his department's inability to do anything until resources are confirmed.

One of the questions that is repeated over and over again is that the department is constantly reacting, which is resulting in continuing crisis. The frustration is, how do you get that message across that it is not a cost-effective way of operating, that we are just going to continue to lurch from crisis to crisis and it is going to end up costing a lot more.

Actually, as a joke a colleague from TasCOSS suggested using cuisenaire rods, so I bought a set of cuisenaire rods along today to actually demonstrate that this is what it costs et cetera. The minister's response was basically there is no money for a proactive approach and as such would raise people's expectations.

Mr MORRIS - We wouldn't want to do that.

Ms BYRNE - There was a question about the need for an accommodation respite task force. He stated that no additional data or scoping is needed, yet that does not translate to the strategic plan. It mostly says to let us have a look at developing working parties to have a look at the scope et cetera. There is no point in planning until the resources are known.

Well, once again that is not a very effective way of operating. The other one that was a real concern was the need for equity of services and transparency. That is another issue that is constantly raised, not just response to the squeaky wheel. His response was that there is no satisfactory way to respond apart from the squeaky wheel and that we need to encourage more squeaky wheels.

Mr MORRIS - We can do that.

Ms BYRNE - I guess that is part of the issue, that lack of forward planning. I guess a separate issue, which I will probably come to later, is the resourcing of organisations that can actually address and support these issues.

Ms BYRNE - The resourcing of organisations that can address and support these issues as well.

Ms LANGDON - I am Mary Langdon from Tascare Society for Children. We are one of the squeaky wheels.

Laughter.

Ms LANGDON - I have prepared a document, but I didn't distribute it before but it looked like you all had very busy spaces in front of you. The reason I came along today is as Tascare is independent we also sit on the committee of HOPES and we are very supportive of what they are trying to achieve. We support BIAT as well in their quest for funding and forward planning in the sector, particularly with the issues that families are facing who have a son or daughter suddenly with an acquired injury - the emotional, social, financial and rehabilitation issues. They are quite significant and we are here to support HOPES and BIAT in their concerns.

Another hat that Sue, Deb and I have is that we are part of the disability unmet needs campaign. It is a new lobby group that has started. We had our first meeting in August and from that I can't stress enough that the major issue that came from service providers, people with disability and other stakeholders was the lack of forward planning in the sector. I have quoted some information there from Disability Services strategic framework draft, where they know there are increasing numbers of people with disability or acquired injury and yet there is always a crisis-management response to dealing with them. We would certainly stress that we need to look at forward planning; we need to get through to Treasury. As Deb said, it is not cost-effective to do things in a crisis mode of management. It is very clear in here. They understand that even in children aged 12 to 15, there are going to be more families requesting supported accommodation and respite - intensive respite - however, we are still in crisis. This has come the full circle; it goes around all the time. Disability Services has broadened its criteria for spinal chord

injury and people with acquired brain injury. They are trying to spread services that aren't really there further abroad and then another crisis will come along. We are very strongly advocating that there needs to be forward planning.

I have quoted from TasCOSS's budget statement. They believe there needs to be an injection of \$10 million into Disability Services. While we would agree that there needs to be increased funding, most of that would only catch up. It is the effective use of funding that is more important than just pouring money into something. I will say the words again: forward planning. It is absolutely crucial and unless we have some structures around that then we will be back here in two years' time and then in five years' time saying the same thing.

Mr WILKINSON - Treasury are interested in figures, obviously; that is what they deal with day in, day out. Has there been any costing done on the benefits of forward planning as opposed to crisis response? If there has, can we get hold of those?

Ms LANGDON - I would like to find out myself. I would like to try to get hold of that through Disability Services, if they would give me that information.

Mr HODGSON - To our knowledge, no, but we think there should be.

Ms LANGDON - We know how much carers save the community, don't we, the cost to taxpayers -

Ms BYRNE - Look at something like a respite service, where a family gets respite. I used to work for the Association for Children with a Disability and I know we came in and spoke to the Legislative Council. The families said they don't want to put their sons and daughters in a group home. They want to be able to keep them home with them - and that translates to all disabilities for younger children - but they need the support to do it. So you have a look at the cost, say, of a four-bedroom group home with high-support needs. You are looking probably at about \$300 000 a year; that is servicing four clients. Then look at what you could get for that kind of money in terms of respite. Our current respite facility has 12 beds, eight of them are full up with permanent placements. You then have that domino effect down the track. Using people with acquired brain injury, for example, the most critical time for people with acquired brain injury is when they are discharged from hospital to community. As I said before, using that intellectual disability model, people with intellectual disability need long-term support. If you can put an injection of funds into that early intervention for people with acquired brain injury coming into the community, then you can address many of the issues that down the track might mean that they do not need that support. If you don't - and once again there is a lot of evidence - people with acquired brain injury are over-represented in our criminal justice system. The suicide rate for people with acquired brain injury is two to five times higher; the incidence of mental illness and other psychiatric disorders is higher. They are at risk of homelessness, domestic violence, assaults and high-risk-taking behaviour so that puts them at further risk of acquiring further brain injury. If you can put those dollars in early and get that intensive rehabilitation in place, chances are that down the track you may not need the long-term dollars. It is the same with the situation with providing families with respite. You are going to stop them going into the group homes.

Ms HODGSON - I think part of the difficulty, too, has been with Disability Services. We have talked about the fact that they broadened out their service from intellectual disability to encompass all disability. The problem was that they were still using the same base when they broadened out. What they did was decide that they must include all disabilities, but obviously they did not have sufficient resources to case manage all people with disability, so they renamed them 'case coordinators', who are not actually managing a case. If you contact Disability Services you might not get to see the case coordinator for many weeks, if at all, and they have no services to forward you on to. So you have a situation where people who were originally employed as case managers for people with intellectual disability have had to try to very quickly broaden their understanding of a range of disabilities, including acquired brain injury, in order to appease people when there are no services to move them on to.

The other issue, as I said, is that for 18 years we have talked about the need for forward planning. The response we have had from the department is that they set up projects, as in the young people in nursing homes project. In 1994 they did a study into the number of younger people in nursing homes. It was to be a two-part study. The first one was to scope the number of people and the second was to look at alternatives because there were people ageing-in-place and this sort of thing. The second part of that study was never done because when they started the first part they got apprehensive about raising people's expectations and were without the funds to do it. My point is that, whilst we are saying that planning is imperative, it has to be planning with a practical component, trailing things as you go. Otherwise we are simply going to go round in a circle and have more and more reports on the table but which don't go anywhere.

Mr DEPUTY CHAIR - Thank you, Sue. Mary, have you concluded what you wanted to say?

Ms LANGDON - Yes, that is fine.

Mr DEPUTY CHAIR - I just wanted to offer you that opportunity if there was anything more you'd like to add.

Ms LANGDON - No, I am fine.

Ms HODGSON - Could we just say a quick thank you to both Graeme and Tim for all the work they did in order to get this here.

Mr WILKINSON - With what has happened over the past 10 years - and we know we have pretty well got back to the start over the last 10 years - do you know how much money the Government has spent - governments of all persuasions - to come back to a position where we were 10 years ago, having spent all this money without any improvement?

Ms HODGSON - We don't - and it would be great if you could find out.

Laughter.

Ms HODGSON - I'm not even sure about the figures for the in-patient unit, but it was about \$4 million, which, as I said, lasted for four years exactly. That was simply gutted and made into offices, so that alone must be an incredible waste of resources. I guess, more

recently, the major costs are related to one-on-one support, very often for people who could be in shared situations but they're not available. Disability Services - I think they are starting to change but in the past few years - have looked at what people's level of support needs are so that you fund a group home. If you need 24-hour care then the people that go into that home are people needing 24-hour care, because that is the only way, economically, to do it. This is probably true if you have a group home, an isolated group home. What then happens, particularly if you have people with high support needs due to challenging behaviour, is that if you put four of these people in together, your support and staffing needs are doubled and the behaviour is exacerbated. In many cases, particularly with acquired brain injury, that sort of behaviour can be modified with a correct program and appropriate people to share with.

Ms BYRNE - It is an effective use of funding.

Mr WILKINSON - Have there been any studies done in relation to effective use of funding to find out the best model to follow for Tasmania, and costings done on that? What the Government will be looking at is how much it is going to cost.

Ms HODGSON - You visited Pellet Street - I guess that is one model. The HOPES model is similar and we had costed that three years ago when we put in a submission. We costed it with three separate support budgets so that we had a response if they said, 'We cannot afford this'; we could actually get the model up and running with people with lower support needs but costing no more.

Pellet Street - Pallet Street combines individual units with a group home situation and I think there are a couple of models similar to that. The difference from HOPES point of view is that we wanted our residents to have ownership of the situation and we wanted them to form a cooperative. Ours is a co-housing model which we have not been able to find currently operating within the disability field, but it does certainly operate very effectively for people who predominantly do not have disabilities.

When we did that first survey in 1993 that Deb mentioned we were hoping to find all sorts of innovative things going on, but in fact what was happening throughout the country was that people were turning to group homes. Group homes then became the benchmark and that has been one problem here. All the costings in sector reform that disability services went through over a two or three-year period - in which all of us, I think, at some stage were involved and into which we put many voluntary hours producing things like client assessment processes and evaluation processes - all went nowhere. The bottom line was that their funding proposals were all based on four-bedroom group homes, which is certainly one model but I do not think it is the only model. I do believe, from what I have seen, that where you have cluster housing, with or without group home involvement, if you have options within, it is more cost effective. That is another issue for people with brain injury; we have some people with lower support needs who need support in the community but also want to feel productive.

Brain injury is something unfortunately that could happen to any of us as we walked out the door today. If it happened to all of you, the likelihood is that you would remember exactly what you were like here in this room today and you would just be restricted in what you could now do. So to be suddenly put into a totally dependent-care situation,

perhaps with people with intellectual disability or people who have the same level of support needs, would I suggest, make life very difficult for you.

What we are saying is that if we can have a mixture of group and cluster housing with on-site support, then the people with lower support needs can actually be utilised in a voluntary capacity to support the others.

Mr WHITELEY - Yes, that is true. Given the level of need in the State, given that big P word that you mentioned earlier on - 'parochial' - and the geographical needs to further that model you just spoke about, how could you set that up? Could you set it up regionally? Could you have that cluster you are speaking about in the north-west? The level of need is there is it not, in each of the regions?

Ms HODGSON - Definitely. At the moment the MAIB accommodation in the south and the north is along those lines, not the HOPES model; it is not a cooperative model.

Mr WHITELEY - How many does that MAIB one cater for?

Ms HODGSON - MAIB down here have a group home which has four people in it at the moment. This is on one site. So in the one cul-de-sac they have a group home for four and they have three units on that site, but one is used as an office - so two separate units on that site. Then they have another five units on a site a bit further down the road. That means that can share support within those two. In the north they have the one site which has a group home for six, I think and units which they are still building or have built. They had two originally and I think now they have capacity for 12.

Mr WHITELEY - So given the level of need, what is the data for immediate and long-term need and what are the numbers looking like for requiring this assistance?

Ms HODGSON - I will start off by saying we do not have actual figures and this is -

Mr WHITELEY - Guess.

Ms HODGSON - something that we feel the department should have but do not have. However, we know that at the moment there is, or a few months ago there were, 155 younger people in aged care nursing homes. The trouble with giving you a figure is that out of that 155 the majority of those people, because they have been there a long time, their families are happy that they are safe and would not want them out. There is a vast but unknown number in the community in family situations similar to mine, and Kathryn is nodding, her head in terms of -

Ms HAY - We just keep hearing it all the time.

Ms HODGSON - Yes, and you do not hear about those until their elderly mother, usually dies or is hospitalised and suddenly you are left with a person who has had nothing apart from mum around for years, which creates problems in itself because they cannot automatically adapt to a change. To try to answer your question, we definitely know that we have sufficient for a small, HOPES-type cooperative trial in each of the three regions. We would certainly have sufficient people to go into there as residents initially, and successfully and I believe economically.

Mr WHITELEY - How many are in each cooperative? How many do you cater for in HOPES?

Ms HODGSON - It is not in your other paper work, but we are currently looking at a proposal for a project at Rosny on the old Rosny Golf Course, which is Clarence Council-owned land. They will be developing a whole-village concept in conjunction with The Association for Christian Homes, who have Snug Village, and Southern Cohousing, who are a cooperative group who have been involved with the cooperative housing in Strickland Avenue in the Cascades. They particularly want housing for women over 55 but they would like to spread. So what we are doing is developing a whole-village concept and within that HOPES would link in with Southern Co Housing for cost purposes and to share a common house. So our plan is to see a common house which would be multi-purpose, from our point of view, would have three respite or transitional beds and an on-site, live-in care coordinator. Then we would have eight to 10 units on site. Those units would be predominantly two bedroom but in a couple of cases we would link two bedrooms together so we would have the capacity for family to live on site as a transitional process.

Ms RITCHIE - I think we all acknowledge that the traditional one-model-is-going-to-fit-everybody mentality is acknowledged as not working and it is not the way to go. I think we all acknowledge that transition to a process where we try to accommodate people as individuals is where we are trying to end up. What do you think are the reasons why this transition seems to be so difficult? When we visited other places, it is all about going to a system whereby we can deal with people as individuals and also try to link flexible funding packages that will enable that to happen. What do you think have been the biggest impediments to that ideal? You have talked about group home as a model and I accept that not everybody will fit into that. Is it a mix of perhaps the State saying we are not sure exactly what way we are going to go, and is it also the tensions with the State and Federal funding models that are going to need to be more flexible before we can ever move forward?

Ms HODGSON - I think it is a fear of cost problem. I do not honestly believe that it is an actual cost problem. But I think that the State department and all levels of government and the agency involved perceive it as such because once you start talking about supporting individuals there is this horrific reaction - 24 hours support for me as an individual in the community would be astronomical. One reason I say that is that when we put in the HOPES submission that was knocked back three years ago, the department came back with various questions which seemed a little strange; obviously they were concerned about cost. Once we thought we had overcome that and explained the costing process, we were then asked how we could guarantee that these people will not have higher support needs later on.

Mr MORRIS - Well, you can't.

Ms HODGSON - I could not. What we are talking about here is not a one-off cost of housing. In bricks and mortar you can go \$1 million or \$10 million or whatever it is; it is a one-off cost and we can walk away and we have done our part. But once you start putting people in and you are supporting them, then whatever happens in the future is going to be ongoing. One of the issues with Pellet Street, for example, is that the three

people they are bringing out of nursing homes are supported through a Commonwealth innovative funds program for three years. The problem with that program for us has been that in theory what you have to do is get your State department to sign off to say that they or someone will take over that responsibility after the three years. I am not sure, but I presume Steve Bracks' Government has said that. However, there are major concerns in Victoria at the moment about this and the three people concerned have said, 'Look, to get three years out of a nursing home we are prepared to risk going back in at the end'. So those long-term support dollars are of major concern. The Commonwealth is very good at doing a one-off, making all these glossy projects so that we can all jump on the band wagon, but there is a very strong end point.

Mr MORRIS - About three years from last Saturday.

Ms HODGSON - Yes. I am totally convinced that our model, or a similar model of cluster housing with a multipurpose house, is the most cost-effective way to go. The difficulty is that we are all working in a very small capacity to get the facts and figures that could genuinely support that. We believed we had done that three years ago. Geraldine Harwood from Optia is another member of our HOAPS organisation and they were prepared to be there, coordinating support providers. They provide support at the moment to various options that they have and so the costings were done on the basis of their costings. So I just think it is a fear of the finances.

Ms BYRNE - I think, Allison, not just with this but with a whole range of issues for which there are solutions, Disability Services is just so caught up with fuelling the existing system - which is not working - which is that crisis-management system. We do not have any dollars for planning. I guess we cannot reiterate it strong enough. The frustration is, we can see the cost savings in forward planning, so why can't Treasury see? The dollars are there; we have seen it. They decided that all people with disabilities should become jockeys or horse breeders because the \$22 million went into the upgrade of Elwick. The dollars are there; we can see the need for the forward planning and the cost benefits, so why doesn't it translate? We recently met with Disability Services to talk about a small increase of funding and they say that their priority is direct service provision, which is basically providing for the current system that we have at the moment.

Mr WHITELEY - It's in crisis.

Ms BYRNE - Yes and I see, as Mary will testify, an increasing number of families with young children, or children who are getting that little bit older, that are really starting to struggle. There is also the boat that probably Sue is in, aging parents with people whom disabilities services either are aware of but are unable to provide support for, or are totally unaware of and there is going to be this collision in the middle. I guess the question we ask is, 'At what point do we say, enough is enough?'. Do we keep putting the dollars into this crisis system and not into forward planning? When do we start being proactive? How do we get the message across? It is really frustrating; you are so many years down the track and there are some many people in the sector who have given up hours and hours of their time. We have a rehabilitation review that still has not seen the light of day for which we all did hours and hours. I can give you here all the comments from the draft strategic framework that they did. They had all these consultation groups and all these people involved in the sector gave up days and days. These are all of the

issues but none of them have been incorporated into the strategic plan. It is just so frustrating.

Mr MORRIS - Is there any chance of a copy of those being left with Charles?

Ms BYRNE - Yes, we can do that. They broke it into five separate groups and they looked at all the different issues. It will give you a really good overview of what the issues are, the whole range of the sector, things about the need for forward planning and transparency, staff training and so on. We can give you lots of evidence about the need for people to be informed and staff to be trained for acquired brain injury, which is one of the roles of the Brain Injury Association. Our emphasis is on prevention. For brain injury, prevention is the only cure. That is our focus but we are really struggling. Disability Services response was, 'Well, you either shut your door for one or two days a week or you do not provide the service'. When I said, 'Okay, that is fine but when we are not providing the service, who is going to provide the training?'. No-one.

Ms LANGDON - I would just like to say at this point that within Disability Services there are some wonderful, committed staff who are working in very difficult circumstances. They are obviously told what they can do with the funding, so we cannot always look at the bureaucrats and say that it is their problem.

How we tap into and get our messages through to Treasury I guess is the point - if we could get your direction on that as well - to effectively reach them with these issues. The people within Disability Services know all of this, anyway.

Ms RITCHIE - I note what you say about additional money from the Treasury coffers but I also have the feeling that it was not necessarily all about getting additional funds. Can you clarify that again? I was left with the impression earlier that you felt that there were funds there but it was really the way that they were being used.

Ms LANGDON - It is how they release it within the disability sector.

Ms HODGSON - I think there are two issues. One is, yes, you could give \$10 million dollars more, but if it is going to go down the same path then it is wasted and you still do not have it. The other issue is another problem that they discover with sector reform. At the moment, because of the way it has been carried out, there are probably services who are being overpaid for services and other services that are being underpaid. Sector reform was all about trying to work this out and even it out but, in fact, it is very difficult. Once a service already has money it is very difficult to say, 'Well, we have changed our minds; we are taking that back now'. That has not happened, so the longer they go on in this crisis mode, the more services will be underpaid or overpaid for what is going on, which, once again, reduces the funds for others.

Ms RITCHIE - I seem to remember there was an Auditor-General's report but I do not know if it was specific to Disability Services. I think it may have been. The guts of the report was that there were some issues with the way that the Department was actually checking and balancing who was able to provide what and how we are making sure that those people we are funding to provide services are, indeed, the correct people for us to keep funding.

Ms BYRNE - But it is not just the non-government organisations; it is Disability Services itself and the services it provides because the services it provides usually cost more than, say, a similar service for a non-Government organisation. The audit of Disability Services is done internally, which has been a big concern that was raised by a number of people from sector reform. For example, the issues that you are talking about concerning vacancies, where the minister came out and said no vacancy will exist for more than three months. We now have 13 vacancies across the State. So what that means if a person moves into an aged care facility and there is a vacancy in the house, the organisation is still getting funding for that person. Disability Services can say 'We want to put this person in here', but the organisation can turn around and say, 'No, I don't want that person', and continue to get the dollars. If you have a look at 13 vacancies, high support needs for a four-bedroom group home are \$300 000, so you are looking at close on a million dollars going into organisations that are not providing a service for a particular client.

Ms HAY - But on what basis can they say 'no' to a client?

Ms HODGSON - They can say that the person is not suitable or the impact of having that person in the home will upset the existing residents. That is another issue in terms of group homes, particularly when you have a small population because you have a small number of people to draw a potential resident from.

Ms HAY - So would you be saying then, 'Okay, maybe it is best for the clientele to actually say 'no' to specific clients, but then the money should not be funded for that amount of time when it is not actually used in that purpose.

Ms HODGSON - That's right. In fact, and I think Allison raised this before, one issue is that ideally you would have individualised funding packages.

Ms RITCHIE - It goes with the client. Where they go, it goes.

Ms HODGSON - Yes, that's right. There is a problem with that in that. If, say, you have four people in your house and they all decide that they want to take their package elsewhere, then obviously the service goes down the drain, so there is a checks-and-balances thing needed. I still think that, ultimately, it has to be the way to go. The other issue with individualised funding concerns how it is going to be managed. If you give it to a family, is it going to be squandered and then they need more or whatever, but those things can all be worked out and there are adequate reports and recommendations on how to do that.

Ms HAY - Is it a little bit 'Big Brotherish' to give more tokens for services that can be provided, so they are entitled to *x* amount of points of whatever and they choose how it is spent and then therefore it is not money.

Ms HODGSON - That's one way that it could be done.

Ms HAY - I know it is saying, 'You can have this', and, 'We don't trust you with money', but it is effective.

Ms HODGSON - That's right. There are several ways that it can be done; I just think that it is something that definitely should be done and would perhaps cover some of these issues.

Mr MORRIS - Can I come back to the MAIB. From what you were saying are they caring for 30 or 40 people or more under their responsibility?

Ms HODGSON - To be perfectly honest I am not sure of the exact number at the moment, Tim.

Mr MORRIS - But it is in that sort of magnitude?

Ms HODGSON - Yes, it could be but the situation with them is that because of their future care legislation and their responsibility for whole-of-life care, it is very much up to the family and/or the person with the disability to determine where and what that care should be. Many of those people are actually living in their accommodation in the north or the south but there are others being supported at home too. I am not actually sure of the numbers.

The other issue is that, for instance in the south, their units are sometimes let out to other people and not all have brain injury - it is spinal cord injury, too, and severe injury.

Mr MORRIS - What I am getting at is that we are actually not getting any concerns or complaints about the way MAIB are running things. They seem to be flexible, cost effective - at least from their point. I don't know whether they are or not; it probably warrants more investigation. They don't have a bottomless pit of money but they do have at least a way, like the Government, of increasing their revenue if they need to. I am just wondering whether there is a lot we can learn for the rest of the sector from the way that MAIB are doing things for the rest of the sector.

Ms HODGSON - I think you will find that it is a fairly costly business as far as MAIB is concerned to get the quality that families are demanding. This was part of the reason for the change from Eskleigh to Anglicare in that they were concerned about the costs. I guess the changes brought certain issues to light. Part of the issue originally was the fact that, because we are such a small population, we need to have viable numbers for people to be able to live together compatibly, all those sorts of things. That was the main reason for wanting to join the two together.

When I was with the Brain Injury Association, I actually managed to get funding for five people to be supported within MAIB house as non-compensable people. One of those people, as an example, had been in Willow Court for 12 years and was considered unable to be rehabilitated or to live in the community. He came out to the house at Montrose on a trial basis for a month, which is probably where I acquired most of my grey hairs, because he actually absconded about three or four times in that time. Ultimately, he settled down and moved up to Launceston to the MAIB house up there because he had family there.

Of these then five people, four were living in MAIB houses and the fifth one is sharing one of the MAIB units with an MAIB claimant. The four are in group homes, three down here and one up north. With the change, MAIB said 'It is not our core business to

support them so they need to go somewhere else'. We had hoped they were not coming to HOPES - we could not get our acts together fast enough - and so Eskleigh built another group home in the south and brought this gentleman back down from the north again. Those four people, fortunately, became known to one another over the years and it does work out well.

There is a whole range of problems but unless you need that mix to get sufficient numbers. I would really like to see some way in which Disability Services can work again with MAIB. Whether that is feasible, I do not know. The original manager was able to work in this integrated fashion. I guess times were different then. Since then there has been a change in management, there has been a change in the way the Government Prices Oversight Commission has looked at these things and the focus is on core business.

Mr MORRIS - They are both working for the same government after all.

Ms HODGSON - That is right and from my perspective it does not make sense in a small State like this to have a two-tiered system.

Mr MORRIS - I might pursue that one further. Rather than put the question to the committee, I might request that we have a talk to the MAIB about their position and, in particular, their relationship with Disability Services. It might be well worthwhile given that Tasmania does have this issue of critical mass and really cannot afford to have this split between compensable and non-compensable when the overriding need is for a critical mass to provide common living conditions. Of course, all people should have the same expectation of being adequately cared for. It sounds like there might be something there that we can pursue.

Ms BYRNE - I should point out that MAIB are funded through their Injury Prevention Foundation, a three-year neuro-trauma register which, in fact, is giving us some really interesting statistics. Unfortunately, though, it only looks at traumatic brain injury, so it is looking at hospital separation. It does not encompass things like stroke. One of the biggest problems is the number of brain injuries that either do not get to the hospital and that are not being diagnosed by the hospitals. The Injury Prevention Foundation also has a charities committee that provides in the vicinity of about \$300 000 to six organisations across the State.

Mr WILKINSON - Having had an interest in it over a number of years, really the whole thing should cease and we should start again, it seems, because to me we have this core service, and, from that core service we have a bit going out here and there but really there is no cohesive pull in the one direction. Everybody seems to be pulling in a different direction. Is that comment right?

Ms HODGSON - I guess that is also illustrated within the department itself. You have Disability Services separated from Mental Health Services separated from Housing Services separated from family and education.

Ms HAY - It is the system they are trying to operate within and they get funding of a certain amount and they have to try to justify and keep it for what they know they can do. They might need double but they will spend it as best they can.

Ms BYRNE - Part of it is historical stuff, with the community institution program. You could have two clients living in exactly the same accommodation with one getting ten times the amount of the other because they would be funded differently. That historical funding arrangement has created a lot of the problems that we are in today.

Ms HODGSON - That fragmentation comes within the hospital system. For instance, you have the hospital responsible here and then they do not want to pay for people to move into some sort of transitional rehabilitation because it should not come out of hospital funds. That is a whole problem in itself.

A classic example is that those five people I talked about before actually came from four separate programs with three different financial years. They are trying to overcome some of those problems but it is still an ongoing issue.

Ms HAY - I just thought I would read this out:

'A resources shortfall does not avoid the need to build effective pathways and sector partnerships. Effective pathways and sector partnerships ultimately ensure best use is made of the available resources and that the best information is available to argue unmet need'.

That is what I have heard all through the day.

Ms HODGSON - That is the fabulous jargon we keep reading but it is unfortunately still only jargon.

DEPUTY CHAIR - Just on that note, are there any final comments you would like to make to our committee today before we conclude?

Mr MORRIS - I would like to thank them for their ongoing dedication and hard work, and for the information they have provided this committee. We will try and help as best we can.

Ms HODGSON - I would like to say thank you very much for, firstly, starting this enquiry off and, secondly, for hearing us today. I realise there are no guarantees at the end of the day as far as this committee goes. I guess our feeling, initially, was supported by Graeme and Tim in that, hopefully, at least an enquiry like this finishes up with some sort of report which we can refer to within parliament.

I obviously have an ulterior motive in pushing this ahead and I do not think I can last another 15 years in terms of transferring my daughter x number of times a day, so I am hoping that all of this will come to something, but thank you for having us.

THE WITNESSES WITHDREW.