

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

**Inquiry into the provision of supported accommodation for Victorians with a disability
or mental illness**

Melbourne — 5 November 2008

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Dr B. Morkham, national director, Young People in Nursing Homes National Alliance; and

Mr A. Blackwood, policy and community partnerships manager, MS Australia; and

Ms R. Hertan, chief executive officer, Huntington's Disease Association.

The CHAIR — Welcome to this public hearing. Could you please introduce yourselves and give a brief summary of the organisation you represent, and then make your verbal submission.

Dr MORKHAM — My name is Dr Bronwyn Morkham. I am the national director of the Young People in Nursing Homes National Alliance. I appear today with my colleagues.

Mr BLACKWOOD — My name is Alan Blackwood, and I work for MS Australia.

Ms HERTAN — I am Ruth Hertan, and I am the CEO of the Huntington's Disease Association.

The CHAIR — Thank you very much.

Dr MORKHAM — First of all I would like to thank the committee for the opportunity to appear before you today to discuss what is obviously a very important issue. We will be talking specifically about young Victorians with a neurological illness. These are the people who predominantly end up in aged-care nursing homes because the disability system as it is at the moment does not have the capacity to respond to their very different needs and expectations.

As with most other First World countries, Australia has experienced a massive surge in demand for disability support and accommodation services that has outstripped the capacity of existing disability support systems to respond, and while Victoria has certainly done better than many states in responding to this growing demand, we still have a disability system that lacks sufficient funding to respond in a timely and effective manner to the needs of Victorians with a disability. As a result our existing system is driven more by the delivery of services according to budgetary constraints than to the needs of the people requiring support. While this reactionary, crisis-driven and risk-averse approach suits no-one, it has particular consequences for people with neurological conditions and acquired disabilities, and, as I said, largely these are the people who end up in aged care.

These are individuals with a variety of degenerative neurological diseases such as multiple sclerosis, Huntington's disease, Pompe's disease, Parkinson's disease and also acquired brain injuries, which may seem to be a bit of an odd one to mention but is by its essence a neurological condition. These are individuals who come along without warning and require an immediate response. Largely they are individuals who have had an able-bodied life before diagnosis or accident has delivered them an acquired disability.

As well as the involvement of disability services these young people also require the involvement of other arms of the service's systems, including health — in both acute and allied health — and aged care. As we know, residential aged care remains the only place in the community where you can access levels of nursing care outside the acute hospital system. They also need housing and community services. These different arms of the service's systems need to collaborate and partner on the delivery of services and not compete for scarce dollars, as they currently have to do. In our view we can no longer pursue a steady-as-she-goes, business-as-usual approach.

This approach is already costing governments millions of dollars in lost capacity as young people — and in this I include the elderly who get caught up in it as well — live in acute care hospital beds because they cannot access the services they need in the community or experience acceleration of disease and deterioration in health and wellbeing because they cannot access support services, including supported accommodation, in a timely and effective manner.

It also costs millions of dollars in the lost wages of carers who provide informal care and then suffer their own health problems as a result of providing this care, with little support over many, many years, and we now have growing numbers of older carers who are experiencing a need for joint replacements because of the work they have had to do, as well as other things.

As a nation and as a state we spend large amounts of money in the health system saving people's lives after they have experienced a serious accident or developed an illness, yet we do very little in consequence to sustain them afterwards. In Victoria we have a two-tiered system of response where if you are fortunate enough — and I use the word 'fortunate' advisedly — to be injured in a motor vehicle or at work you receive fully-funded lifetime support and all your disability support needs are looked after including accommodation. Yet if you fall outside these two areas you end up on an ever-growing waiting list where waiting is very likely to result in an exacerbation of disease with unintended health consequences, a consequent increase in costs over the long term and referral to residential aged care as the only available option.

The key to managing the consequence of these diseases is managing the disease symptoms across the course — or life cycle — of the disease, and mostly this happens in the community. Doing nothing is going to cost us more than recognising the need for change and the need for responsible funding of the leaders of that change. We believe that the delivery of supported accommodation services for individuals with neurological disease and acquired disabilities first and foremost requires a capacity to work with the individual and their family. It requires absolutely a recognition that the supply of supported accommodation services involves far more than the supply of a building and the placement of individuals in that building. It includes staffing levels and staffing models. You need different types of staffing to deal with certain types of disability or illness. It involves social inclusion provisions; it involves allied health; it involves workplace training, support and mentoring. I guess one of the key points we want to make today is that when we are looking at supported accommodation we cannot divorce that from all the other things that attend around that and make it work — or not.

It also means acknowledging that different disability types require different suites of responses. We need to recognise that as neurological diseases progress funding levels need to increase too, and at the moment that does not happen. If you are lucky enough to get into a supported accommodation service, often that is where it stays, yet as your disease progresses and your needs increase the level of funding to provide that support does not match it, and so we have a fall off in services. These are usually quality-of-life services, community access and so forth. Allied health is a really important one here, and that tends to fall away as well. And for these young people allied health services are essential to sustaining their level of health and wellbeing over the long term.

We also believe that implementing a whole-of-life approach to the development and supply of support services is a fundamental thing that we have to do. We believe that pursuing an insurance-based approach to future funding for disability services is also essential. We are aware that governments are unable to provide the funding that is needed with this growing level of unmet demand that we have now, and are going to face more and more in the future, and an insurance-based approach will help to deliver those services in a timely and effective manner.

In concluding — I will then hand over to Alan and Ruth to offer you some case studies of individuals that fit within this area — I would like to say that as we all know this is an issue that affects every one of us. It is not about them and us, it is about all of us, and is above politics as a result. We look forward to the inquiry delivering a unanimous report that will enable the disability sector to embrace the changes needed in a spirit of collaboration and partnership at all levels.

Mr BLACKWOOD — I will go through a case study which illustrates the waiting-list approach to dealing with disability; it is probably the biggest enemy of a person with a progressive illness because the disease does not stop and wait for someone to fly to the top of the waiting list to receive the service.

We worked with a particular lady, not so long ago, who was living in the eastern suburbs in a modified Office of Housing unit and was receiving about 5 to 6 hours a week of home community care support for home help at a fairly low level. She had an electric scooter which was provided by the aided equipment scheme and was living fairly well. She had a major disease exacerbation which meant she had to go to the local hospital and she was there for some weeks. When she was

ready to be discharged she needed a substantial amount of increased care, and because her homecare package was so small the hospital was not prepared to discharge her home. They considered it to be unsafe, because she needed all this extra care. An application was actually made to the Department of Human Services for an in-home package that was larger than a 34-hour-a-week package, but of course it was not available within the few days she had before the hospital was going to discharge her and so she was discharged to a nursing home, where she still is today.

Her disability package was offered to her six months after she had moved into the nursing home and a place was also made available in a disability group home that she could have taken but by then she had actually lost her desire to return to the community. She had been so traumatised by the move into the nursing home that she did not trust the system to offer her something better. It was a case of for the want of a few hours per week she actually lost a lot more than a number of other people. She had a modified unit, she had all her equipment. When she moved to the nursing home she had one of those big scooters that she used to be able to use outside, she was not allowed to use it inside the nursing home because it was too big and was a danger to other residents. She was not allowed to use it outside unsupervised, so she lost her mobility as well because the aged-care system would not allow her to express herself in the same way that the disability system would allow someone to access the community. She had a major reduction in quality of life and opportunity, from which she never recovered. This woman was around 50.

There are a lot of consequences happening to individuals because of having to wait for the services because the diseases like multiple sclerosis will take their own course. Bronwyn mentioned an insurance-based model, and it is important because we really need a system that can keep pace with people's needs and would enable them to achieve the things that the disability system wants for people, which is to stay in the community, to stay engaged with their family, neighbours and friends. They are often forced into situations where they live in places not of their choosing because that is the only place where they can get support. Unfortunately that often means aged care.

Ms HERTAN — I have a couple of case studies. I just wanted to tell you a little bit about Huntington's disease. You may not know very much about it. Huntington's disease is very much a family disease. It is a brain disease that is inherited through the family line, so everyone who has a parent with Huntington's has a one-in-two chance of inheriting it. It is a degenerative brain disease, so it kills off brain cells over 15 to 20 years and people gradually lose their ability to move, to think, to feel emotions and to talk. Eventually they have trouble eating, swallowing and breathing. It takes 15 to 20 years and it is invariably fatal. It is incurable, and there is very limited treatment at the moment. Some symptoms can be controlled with medication.

It is quite a rare disease. In Victoria we have about 400 people with symptomatic HD, which means they have actually got it at the moment. There are another 2500 to 3000 people who are related to those people and now have a one-in-two chance of getting it. Of course for every one of those, if you think about your own family, there are several other people around. I would say there are 10 000 to 15 000 people who have someone in their family who has Huntington's. The social and economic impact of this illness is enormous.

Even though it is very rare disease, people with Huntington's are disproportionately represented in terms of people who fall between the service gaps. These case studies will illustrate that. Both of these are ladies in the early 40s. One has presented with behavioural problems. She was one of six children; three of whom have developed Huntington's disease — pretty typical. She did not show symptoms until she was in her 40s, and by this stage she had two children herself and several grandchildren. You can see the impact immediately there. Her son has been diagnosed with Huntington's; her daughter's status is not known at the moment; and her mother died of Huntington's four years ago.

When she was diagnosed in 2002 she was living independently in the community with the support of a Linkages package, but within a year her condition had rapidly deteriorated and she had to move to supported accommodation in order to just get her basic needs met. This placement did not last long. One of the things about Huntington's is that it is very individual in its approach. Some people have just motor symptoms, some people have a range of combinations, in some people it is cognitive, and some people present with quite serious behavioural problems. That is what happened to this lady. She became quite violent and aggressive towards the staff and was unable to remain there. She ended up being admitted to an acute psychiatric ward, where she stayed for six months. Again, this highlights that there is no facility anywhere to put someone young, in their 40s, who has got younger onset dementia like Huntington's presented in her case. Psychiatric units do not consider that Huntington's is a psychiatric condition because it is a medical condition. It is a disease and not a psychiatric condition and one of those very fine lines of delineation, so they are always trying to discharge her; they are under pressure to discharge.

Without our knowledge, she was discharged to another residential accommodation where her behaviour worsened. She attacked people and she had to go back into another acute psych ward. In six months it was the same story again. During that six months, 17 supported accommodations refused to take her because of her history of violence and aggression. Eventually they discharged her to an aged-care nursing home, and within two days she attacked one of the staff — in fact, two of the staff — so she is back in a psychiatric facility and there are no options for her; there is nowhere to put her. Her family have to visit her there. Not only is there nowhere to put her, there is no social engagement, there is no quality of life, there is nothing.

She is one of a dozen case studies I could give you like this. We currently have five people in the Royal Talbot Rehabilitation Centre and we have had to be really strong advocates to get them in there because that is a rehabilitation facility. People are meant to stay there for a few months with an acquired brain injury and then move on back into the community. Our people need to be there for several years until their physical deterioration stops them from being able to be a risk to themselves or others, so the rehab centre is very reluctant to take on any more. We are occupying half of one of their houses at the moment.

What we find, though, is that in a place like that where there is a rigid structure, a really great timetable, staff who really know what they are doing, the behaviours improve enormously because people feel secure and they can cope with those sorts of things.

That is one. The other case I would like to tell you about is just to illustrate the problem we are having with ACAS services at the moment, because obviously since the introduction of initiatives like My Future My Choice people under 50 are getting dealt with very well, but the people between 50 and 65, which is the bulk of our clients, just do not have an existence anymore. They do not fit, because a system that categorises people on age rather than on need makes that age group, 50 to 65, invisible to the system.

Another young woman, a mother of two young children, had very rapid deterioration. She did not have a behavioural presentation; she just had cognitive and physical deterioration. ACAS refused to assess her because of her young age, so she ended up in a psychiatric ward, and eventually after an enormous amount of work from my staff lobbying and lobbying and going through all the groups, ACAS agreed that it would assess her if she trialled supported residential accommodation. This was a woman who absconded. That was one of the features of her — she absconded 17 times. I do not know what period of time that was over. She put herself at enormous risk, sometimes ending up 20 kilometres away from this place. She put herself and others at risk, so back into the psych ward she went, where she spent 18 months, and her 10-year-old and other child had to visit her there, knowing that they were themselves at risk of this happening to them.

You can just imagine the enormous impact on the family of this kind of distress. In the end, the Arthur Preston Centre, which is Huntington's-specific accommodation, had a vacancy, and she has gone in there and is doing really well in there. Why is she doing well? There is a higher

staff-to-client ratio, and there is a fantastic program of social supports. They are going out, doing activities, and she is there with other young people. She is in an appropriate place. Again it highlights that the bricks and mortar is not the thing that resolves it; it is the social.

Mr SCHEFFER — Talking about the examples that you were mentioning, Bronwyn, what would an ultimate model look like to you?

Dr MORKHAM — That is the \$64 000 question. I guess the answer to that is a range of options on the spectrum is what we really do want.

Mr SCHEFFER — Which is what we hear from everyone.

Dr MORKHAM — That is right, but it is true. I think the key to that is to work with young people and their families. This is not about apportioning fault, it is just recognising that we have a system that has grown in the way it has for a range of reasons, and we need to change some of that. At the moment the system tends to build something — —

Mr SCHEFFER — Can I stop you there. How would you characterise what has changed?

Dr MORKHAM — In?

Mr SCHEFFER — A number of witnesses have talked about how the situation, in a generic sense, is more complex these days: there are more stresses; there are more variables; there are complexities of need. Would you subscribe to that, that there has been a shift in what we are looking at?

Dr MORKHAM — Absolutely.

Mr SCHEFFER — Or have we become more sophisticated in analysing it?

Dr MORKHAM — Probably a little bit of both, but I think for our group we are very fortunate in this country to have access to a wonderful health system, the latest medical technologies that save lives that once would have been lost and enable people with degenerative disease to live for longer with a better quality of life, as they do. We are now seeing a bigger group of people coming down the pipeline with very different needs to those the system is organised to deliver on at the moment. Yes, I think it has significantly changed. We are also a little bit better at identifying, but in a way the identification is almost secondary, because you cannot access the supports that you need to provide the right level of support to these young people.

I guess in terms of where the system is at the moment it tends to be a very top-down approach. We understand budget constraints absolutely, but in fact now the system takes that as its departure point. One of the big problems, we believe, is the fact that we have a bifurcated system that delivers anything according to how old you are, when it should be according to the level of need you have, not how old you are.

With the COAG initiative, which is a wonderful first step — and it is purely that, a first step, yet it has been seen, I think, as the only step in some cases — one of the biggest disappointments was the reinvention of that age-based need through the delivery of an initial target group of under 50 years of age; yet we know that most of the people who end up in nursing homes end up there because their informal care arrangements break down or their level of disease accelerates because they have not had the supports, and they fall essentially around the 40-years-of-age mark.

From about 40 to 50 years of age there is an absolute spike in the numbers going in. In Victoria, for example, out of about 1700 people in aged care under 65, only around 220 were able to access that initiative. That is wonderful, on one hand, for them, but the other constraints that initiative

carries have meant that it has not been able to address the really critical reform areas that we need to look at and act on. While there have been efforts — —

Mr SCHEFFER — So if we premised a model, as you are saying, on the base of an individual need and the complexity and layering around that, do you know of examples, either in Australia or globally, where such a structure has been devised?

Dr MORKHAM — I do. I mean, I would have to qualify that response by saying that in the ideal world you would start with a young person and their family, but of course there are other things that come in to intervene there, so it is not as pure as that. But we were involved with the MS Society in the development of a supported service in Beaumaris that was for young people living in nursing homes. It takes a range of disability types, so it is not specific to any one. What it has been based around is the level of need. It is for people with low-to-medium support needs. There is an understanding that once people go in there, if their level of need rises beyond that which the service can support, they move. The terrible thing is there is nowhere for them to move, so that service often has to hang onto people who it struggles to support.

The other point about that service is that there was involvement of the local community in the development and design. As with many of these things, local communities know very little about these issues. They fear them — fear of the unknown — but a lot of work was done with the local community to make them aware of what was happening, why it was happening and how they could get involved. The local community is now probably the fiercest supporter of that service — actively involved. The young people who are there are actively involved in the management of the service. They are heavily involved in their local community. It has been an absolute success on every level.

It has also got a mixed equity approach, so that if a young person has capacity to buy in and own their own — I should have said it is a series of fully self-contained, one-bedroom units on one site with 24/7 support delivered on site. People pool some of their support hours to have that 24/7 approach there. Just to give you two examples, there were three residents; one resident did not want to involve themselves in cooking their own meals at all, which is something I can quite happily identify with, because I do not either. They did not want any involvement in that. They wanted somebody to cook the meals for them. Another couple of residents wanted to have choice about what they ate, and they wanted to have some involvement in the cooking of the meals, so supports were put in place for that.

Another couple of residents decided that while they did not want to actually physically cook the food, they wanted control over the menus and how and what they ate et cetera. They were supported to engage a chef who came in once a month. They worked with the shift to devise the menu for the forthcoming month, the chef bought the ingredients, cooked it up and packaged it up into single-meal amounts that were then frozen for the month. That just gives you an idea of how people were encouraged to have very individually based support programs developed and could quite happily do that within the services that existed. As I said, the sad thing is that there is just nowhere else, if your support needs increase, to go to from there. But that would be one standing example.

Another one would be for people with MS in Western Australia where six fully self-contained, three-bedroom units were developed there, again to bring in whole families. This, again, is another of the issues we wanted to mention, that we should be looking to support families. I think the disability system with regard to accommodation largely assumes everybody is an individual, but for our group they are not. They come with a family and often with small children attached.

But we do not have capacity to move the whole family into such a service. This place did — 24/7 support provided on-site. The entire family moves in so that the partner who is still able-bodied can continue to work. The disabled partner gets whatever they need during the day, the children

are able to go to school and the family unit remains intact. That is another example. There are some examples of really good things working out there already.

Mr BLACKWOOD — The other thing is, when you are talking about an ideal model, we actually have a system in Victoria that is world class in the Transport Accident Commission, mainly because it does not have to do the sort of policy gymnastics that we see at the Department of Human Services, trying to actually make a very small resource go a long way. There is guaranteed lifetime support for every person who has got a catastrophic disability. Some of the decisions around where people live, what sort of support they get, whether they choose to live in shared supported accommodation or at home with their families is actually a real choice, because the support is already there.

As much as we need to look at the service models and how the service gets delivered, I think we need to look at some of the financing models for how we actually fund it. If we can unlock some of those policy constraints from having to have policies that do not make any sense but they meet the budget requirements, we can actually start getting to the meeting of needs.

For most of our conditions, particularly those progressive neurological conditions like MS, Huntington's and Parkinson's, the shared supported accommodation part — and you might include out-of-home respite in that — is really just a step along the journey. To look after someone's lifetime care needs, you have got to start with disease management principles, medication, financial advice, family support, carer support, home care, home modifications. If someone can no longer live at home because of family breakdown or their needs have become extreme, then they actually need an appropriate place to move into.

The numbers in Victoria are fairly mature. We actually know how many people come through every year, and yet the system does not have the capacity to prepare for them. Everybody comes to human services in a crisis — 'What do we do?'. They come in groups of one. Suddenly there is a whole lot of resources that need to be marshalled where there are none. It is a very difficult thing to do without that preparation.

The MS Society along with Bethlehem hospital are running a pilot program. It is called the continuous care pilot. We are actually looking at articulating support from a range of programs, including disability services, HACC, Rural District Nursing Service, hospital services — assuming that if people need three or four services from through four different programs they should actually access them all at once. They should not be forced to relinquish one as they move to another, which we see quite often. If someone outgrows their HACC service and moves into disability services, as soon as they get a disability package they are forced to relinquish their HACC package, which does not make sense if they actually need the quantum that both provide.

There is a whole lifetime support model that we need to develop. As I said before, part of the trick in doing that is to actually finance it properly. Otherwise it becomes just an intellectual exercise in how you plan. I think we have seen a lot of examples from the commonwealth and the state government where the proof of the pudding that people are offered is actually in the plan. People will be guaranteed a plan. There will be a huge announcement — and the federal government has done this with its national respite for carers program, where it will actually give ageing carers and families an opportunity to plan for their future, but then there is nothing behind it. It is like inviting someone for dinner and giving them chewing gum. There is no substance to the plan. Whereas with something like an insurance scheme, there is the plan and the funding to actually implement it, which is the really important bit.

Mr NOONAN — Can I just be clear on the insurance project. You talk about workplace injuries or road accidents, but they are funded by people paying a premium. I just want to be clear; when you talk about an insurance-based approach to funding, are you talking about the

government simply allocating, or are you talking about some other sort of contributions coming from somewhere to underpin that insurance-based approach?

Mr BLACKWOOD — It would need some kind of premium to be levied.

Mr NOONAN — Who would pay it?

Mr BLACKWOOD — Currently in Victoria there is consideration of a catastrophic injury scheme which would cover things like the violent assaults we see most weekends, where people sustain brain injuries — they are not compensated. Public liability, the domestic accidents — if someone is cleaning their gutters and they fall off their ladder and hit their head, that is not covered — and all the gaps.

Dr MORKHAM — Sporting injuries.

Mr BLACKWOOD — Sporting injuries is the other one. There are some things that are currently insured in pockets — public liability and other types of insurance; they could be put in the pool — but ultimately it would need some kind of levy to be put somewhere, whether that be on local government rates or loaded onto the Transport Accident Commission charge. That is really something for government to decide. There would need to be a certain amount of money levied each year to cover the needs that would come from that group. The discussion around a catastrophic injury insurance scheme as a sort of companion scheme to the Transport Accident Commission is really for that catastrophic level of disability; it is not like the New Zealand accident and insurance scheme for any injury of any type, whether it be a sprained ankle or a twisted knee. This is serious, lifetime disability.

Mr NOONAN — The way you have described it means it would not cater for Huntington's, for example.

Mr BLACKWOOD — In the first cut, if we are talking about injury-related, it would not, but we say that neurological conditions are eminently insurable because they are reasonably predictable in terms of number and disease course. Even though everyone is different we kind of know the numbers and the type of support that is required. Really the challenge is where to put the levy in terms of being fair to the community. We accept that driving a motor vehicle is an inherently dangerous pursuit so we have an insurance scheme to cover it. Going to nightclubs is now a very dangerous thing to do, as well as playing sport and walking down the street. It is not the cause of the disease that is important, it is the consequences. Whether it is Huntington's or MS or a brain injury or a spinal-cord injury that is received on the sporting field, the community has to provide for that person for the rest of their life. If they do not do it in a planned and appropriate way that person may end up in a nursing home which then keeps an older person in an acute hospital bed, which means that a person who turns up at the emergency department has to sit on a trolley for 48 hours because there is no allocated efficiency in the system.

Ultimately the best solution is the most appropriate one. It is really just about the community getting its head around the fact that disability and lifetime care is an important thing that we all may need. We all drive our cars but it is assumed that we will not end up with a catastrophic disability. But for 120 Victorians every year that actually happens, and there are a number for whom there is no support, and we have seen some media attention for some of those individuals who have a lifetime care need but there is no support; they rely on the political budget process.

Mr NOONAN — Others have said that where people have the means to perhaps provide some support that the system should allow that. Is that something you would advocate for as well?

Mr BLACKWOOD — Can you say that again?

Mr NOONAN — We have had others, particularly ageing carers, who might want to put their property in a trust arrangement to provide some security for the person they are caring for. Is

that a model you would advocate for? I think what you are suggesting is that there is potential for contributions to be made in terms of the funding stream to assist in this area.

Mr BLACKWOOD — I think it is a bit like what Bronwyn was saying before about the service model in Beaumaris where people can make a capital contribution. I think the critical thing is the recurrent service costs. If someone has a service need it is very hard to have the quantum of money that would provide that stream of income to pay for the ongoing support. They are two different questions about providing capital for a place to live and also the funding for support. Really the support is the critical element in maintaining yourself in any place that you might be able to afford.

Ms HERTAN — I gave you an example of someone with Huntington's. To keep someone in the Arthur Preston Centre for a year costs about \$100 000. I do not know what it costs to keep someone in a psychiatric ward for a year, but if you think about the enormous cost and the add-on cost of what it does to the family and then what the burden is going to be on the health system, there is a huge saving in actually creating appropriate accommodation for people like that.

Ms WOOLDRIDGE — Could I just ask for one piece of data if you have it? I would be interested to know about the 1700 young people in nursing homes. What system have they come through to get there? What accommodation has not been available for them to end up in a nursing home? Is that data available?

Dr MORKHAM — Not really. Like many areas we are fairly data poor in this. I think that will start to change, but anecdotally we know that people usually enter from acute care. As Alan was saying with that example, people go into hospital either because an accident produces an injury or because of an exacerbation of illness. While they are there they are fine, and the hospital will hang on to them for roughly six months and will do what it can do, but then it needs to move them. Usually it is an express route to a nursing home because there is literally nowhere for them to go.

Most of our group need a modicum of nursing care to continue to recover from whatever it was. They cannot go anywhere else to get that outside the hospital other than a nursing home. I think way back when this issue really started nursing homes were always seen as an interim option. They were there until something else was developed, but because of the lack of funding in disability services, which has been endemic from the get-go, there has never been a capacity to develop those other places.

I guess one of the things we want to see, and addressing insurance is an option, is to try to inject the funding into the system that it so desperately needs. If we do not do that, we are going to go around in circles. As Alan was saying, we can talk about plans and we can talk about what results we want, but without the financial capacity to deliver them we will go nowhere.

Just on that, we have supported the development of that catastrophic injury insurance scheme in this state purely because the catastrophically injured are the most expensive group to rehabilitate and support. They soak up more disability dollars than any other group, and if we could ship them out — and there are about 80 Victorians a year who suffer a catastrophic injury from one or other of those causes — we would release significant capacity back into the disability system. The challenge though is to maintain the level of funding support disability receives and grow it. The disability system cannot say, 'We have now got a bit of extra capacity. We can just sit down and that is all fine'. That is why we support that very firmly.

Just in answer to Wade's question before, if we were to add to the Transport Accident Commission levy, and it was added to the costs for the 4 million Victorian motorists we have, it would cost only \$20 a year; that is it. It is not a large amount of money. It is three or four coffees a year. One of the biggest challenges we all face is making the public aware that every single one of us is at risk of entering a nursing home unless we get a system in place to support people.

We see that catastrophic injury scheme growing. As the scheme progresses it will grow out. The next tranche might be medical misadventure; it might be medical indemnity. It will then go to people with progressive neurological illness and so on and so forth. Ultimately we need a system that is based on need and not age, and which can help those people who are currently in aged care as well.

The CHAIR — Thank you very much.

Witnesses withdrew.