

THE PARLIAMENTARY STANDING COMMITTEE ON COMMUNITY DEVELOPMENT MET IN PERTH ON THURSDAY 12 AUGUST 2004.

INQUIRY INTO YOUNG PEOPLE WITH ACQUIRED DISABILITIES

Ms JANET WAGLAND AND Ms LYNNE HO, BRIGHTWATER CARE GROUP, WERE CALLED AND EXAMINED.

Ms WAGLAND - Brightwater is a very large organisation that has about 20 facilities and has been in existence for over 100 years now. Its main name is to provide care for the whole community, so it looks after aged as well as young people. Its main core business is actually care for people who are elderly, and it provides those services through some special needs accommodation. We have four nursing homes that have some top-up funding from State Government that provide extra services for people, and some young people are actually accommodated in those facilities. It also provides standard nursing home and hostel care, and some in-house care, both DSC-funded and Commonwealth-funded, and that is called our At-Home Services Branch. But the side that we are working with is our Young People Services. The majority of accommodation that is provided under Young People Services was funded originally through the Young People in Nursing Homes project that was commenced in 1996, a State Government initiative on the back of a report by a lady called Jo Stanton, which was produced in 1995 to look at issues for people with an acquired brain injury and the lack of services that were available for them. Accommodation was a really big area that came out in that report. We also encompassed under that group people with Huntington's disease, so we have facilities that provide accommodation for people with acquired brain injury and we have a facility that provides accommodation for people with Huntington's disease, but we also have had some additional funding to provide a 10-bed transitional rehabilitation unit that is based on this site, and that is for people who need a slower stream of rehabilitation past the post-acute stage rehabilitation that they go through at our Shenton Park facility.

CHAIR - Is that similar to the Slow to Recover program in Victoria?

Ms WAGLAND - The Slow to Recover program I believe is attached to nursing homes, isn't it?

Ms HO - It is based on providing care to the same type of client group, but we use a different model. They fund the client in the facility where the client is, and design services individually and keep reapplying for funding according to what is required on a sort of cyclic basis. We have a funded facility, and we provided whatever is needed in-house.

Ms WAGLAND - The additional service that we provide is the Oats Street facility, which has been in existence for about 12 or 13 years now. Oats Street is also a slow-stream form of rehabilitation for people with acquired brain injury. It has 24 beds and it provides that rehabilitation for people who are eventually going to move into community

living, so they are a higher-functioning level of person and most of their issues are those of cognition rather than physical issues by the time they get to that stage. So the services are really diverse, and even in the community houses there is a huge amount of diversity in the level of need of the residents that are there. You will see that the residents here in Endeavour are very high need, and have a number of gastrostomy feeds, so there is that high physical need. The facility at Manning is the opposite end of the scale, where the residents are accessing TAFE and work and recreation facilities so that they are actually a lot more outward. They are participating in cooking in the house, and are very much more independent, and the other community houses provide a spectrum of care between those two extremes.

Ms HO - Okay, so on this site we have a total of 31 beds. It is made up of Endeavour House, which is our high-support needs group home, which is funded by DSC, and in that grouping we have a group of clients who are PEG fed. The remainder do eat modified diets. We don't have anyone who walks. We only have one person who talks effectively. Everybody else is on the very high end of the scale. Predominantly the clients have an acquired brain injury, more than ten years post-injury. Often in the past it was thought that people would not survive for a long time, but they actually do survive for a very long time. Their life expectancy is not a great deal shortened, and so people need to plan very long-term for the care of these types of clients. We have a few privately-funded clients who have acquired some income through compensation payouts, and we have three beds for that purpose which are not Government-funded at all. Those clients have individually designed packages and costings through Brightwater. We have the 10-bed rehabilitation program which is for slow-stream recovery clients. The most successful clients in that group will move forward to Oats Street. The least successful we would hope to accommodate within Brightwater in the nursing home model. That program is Health Department-funded, and we are licensed by the State Health Department as a nursing home, so we have to meet the Disability Services Commission standards as well as Health Department standards on this site.

We have six houses on site. The buildings are about ten years old. They were modified for us about four and a half years ago when we moved the clients from the old nursing home models in Brightwater, which used to be six to a room with the bathrooms down the corridor, a very old-fashioned hospital-based type approach. The Young People in Nursing Homes program took us three years to complete, and it is about three years now since we finished it, so it was a big project.

Mr WHITELEY - The rooms here now with the upgrade are all single?

Ms HO - We have a double room in each unit. Otherwise it is a single room with ensuite bathroom. When we moved we did get a very generous funding package for equipment, so we have brand new electric beds, lifters, shower equipment, really the best available in this facility, because the clients are extremely heavy to move and we have to be very safety and health conscious, particularly when you look at the cost of workers compensation insurance now.

Mr WHITELEY - Can I just clarify for the record, Brightwater is State funded? Is it a private company? Can we just clarify that?

Ms WAGLAND - Brightwater is a non-government organisation, not-for-profit. The majority of the beds are funded through standard Commonwealth nursing home funding. Some of those beds have State Government top-up and they are the special needs facilities. We also have the At-Home Services packages which are a mix of Commonwealth-funded aged care packages as well as Disability Services funded in-house packages, and all of the Young People in Nursing Home beds are Disability Services funded. The rehabilitation program here is Health department funded. The one at Oats Street is Disability Services funded, and also on top of that we have a few respite beds and they are Health Department funded, so we are real mix and match.

Mr WHITELEY - What about the capital costs of all the properties at Brightwater?

Ms HO - This is Brightwater property, so all of the six buildings on this property belong to Brightwater, and Brightwater has its own internal maintenance service. They do all the scheduled maintenance, meet all the requirements, standards and so forth. Some of our other facilities, such as Balcatta, Maylands, Manning and Ellison, are Homes West properties - that is, State Housing.

Mr WHITELEY - Housing Commission.

Ms HO - Housing Commission, yes.

Ms WAGLAND - Warnboro is. Ellison is Brightwater-owned.

Ms HO - Yes.

Mr WHITELEY - So how does Brightwater then actually fund the return on the investment of such capital costs as obviously you have across the whole State? Is that then funded out of the individual's benefit paid fortnightly; or how does that actually work?

Ms WAGLAND - Basically all of the total upkeep of buildings and everything comes out of the funding package that we get originally. With the Ministry of Housing facilities, the Ministry of Housing is responsible for anything that is structural. That is fairly loose and basically they do nothing. We do most of the maintenance costs for those facilities. We are also responsible for a lot of the equipment funding. Across Brightwater, most of the equipment is maintained and funded by Brightwater itself. In the Disability Services Commission-funded facilities, if a resident requires an individual piece of equipment like a communication device or a wheelchair or even a specialised commode, that is purchased through the Community Aids and Equipment Program, but is provided through the Disability Services Commission. They also pay for maintenance of the equipment attached to that, so we have to separate out those pieces of equipment and make sure they get channelled through that. They also give us some funding through the Contenance Aids Scheme for all of our Disability Services funded people as long as they are under the age of 60, I think it is. And another issue is the Ageing in Place, as well.

Mr MORRIS - How many people are coming new to you each year, for example?

Ms HO - On this facility we try to turn over the 10 beds in the rehabilitation program over every 18 months. Private clients stay permanently, and in this last 12 months I have only turned over three beds in Endeavour House. That was due to one client's needs changing

to aged care, one client passed away, and one client's family chose to move him to a different suburb.

Mr MORRIS - Do you have a big waiting list?

Ms HO - We don't carry a formal waiting list because we have inquiries, we keep lists of names, but because the beds come up so rarely it is just not practical to keep a waiting list for someone who is sitting in a public hospital or who is in great need at home. Most commonly within Brightwater, a Brightwater client is a member of the Brightwater family, and would be the first person reviewed for an available vacancy.

Ms WAGLAND - Although, having said that, the Disability Services Commission are currently under the pump a bit from the Commonwealth Government, because the Commonwealth also provides a component to the Young People in Nursing Home beds. They provide us, I think, about \$13 000 or \$14 000 a year per bed in funding to keep people out of nursing homes. They are now talking to DSC about the beds the Cerebral Palsy Association has from that scheme, and also the MS Society. The Fern Road beds are all Young People in Nursing Homes, and with our Young People in Nursing Home beds we are looking at how we provide the waiting list and how we select people for that, because their aim is that we would be pulling people out of nursing homes, and that would be a first preference as opposed to somebody who is at risk of going into a nursing home. So it is a bit of a debate at the moment, because our argument of course is that for somebody who has been in a nursing home for anything up to 10 years it is very difficult to then relocate that person into a community house, because it is disruptive for them and they have become a bit institutionalised anyway. We would rather stop somebody going into that in the first place. So it is something that is being debated at the moment, and it is all part of DSC having to justify that Commonwealth component of the funding for each of the beds.

Mr WHITELEY - Can I just have a clarification? You mentioned \$13 000 or \$14 000 that is like a special fund to literally keep people out of nursing homes. Could you just talk to me about that fund - who funds it, how did that start, what drove that fund?

Ms WAGLAND - My memory of it, from when we were first moving people out as part of the Young People in Nursing Homes project, is that it was called the Commonwealth Nursing Home Beds Subsidy Scheme, and they provided that funding alongside of the Disability Services Commission funding for each individual bed, to remove people who were in nursing homes. All of the people who originally went into the Young People in Nursing Homes accommodation were either accommodated in Brightwater's nursing home facilities or in a large facility called Mt Henry that was sort of half hospital, half nursing home. Mt Henry got torn down so it no longer exists. Brightwater diversified and decentralised and went from two very large facilities plus Oats Street into what we see now, which is up to 20 facilities spread across the whole of the metro area. So in doing that we moved our residents out into that accommodation at the same time and there was that component that was Commonwealth funding. DSC would have a greater understanding of how that works, because the funding actually comes from the Commonwealth to them. They then give us a bulk funding on a yearly basis, or I think they pay us quarterly.

Mr WHITELEY - What about assessment? We have ACAT, Victoria had ACAS. How does your assessment work at a State level? Who does the assessing?

Ms HO - Okay. For the rehab clients we have a screening tool. The referring hospital will complete the screening tool and forward it to our central admissions service. They will forward it on to the most appropriate care manager, either myself or Janet, and we will discuss amongst ourselves who should assess the client. We go and assess the client and work out which facility we feel is most appropriate, or whether or not we think we can provide service. Then there is a second level, the teams meeting and discussing the client, working out a waiting list and then allocating according to priority who would come in next.

Mr WHITELEY - Are you saying then that, other than older people going into nursing homes, there is no official State-based assessment team?

Ms WAGLAND - There are the ACAT assessment teams, of course.

Mr WHITELEY - They are for people over 65 who are going into nursing homes.

Ms WAGLAND - That is right. And they have become extremely strict for anybody who is under 65, and they have actually documented now that their priority is people who are over 65. They will only look at somebody under 65 if we have explored every other avenue. So we have to have documentary proof that they have been rejected for DSC funding, for funding from any other group, that they can't be accommodated somewhere else. So if you have tried all of those avenues then you may be able to get an ACAT team to assess them, and the younger they get the more and more difficult it is to access that. But, apart from that, each of the individual organisations do their own assessment for people coming in. I think that CPA might look at piggy-backing a little bit with us because they have fewer Young People in Nursing Home beds, and we actually have more access for people who are already in a nursing home system, so certainly we do prioritise our existing residents who are in the aged-care system if we get a vacancy, so they would piggy-back a bit into that. But for final selection, each of the individual organisations do their own assessment, because they have to judge whether that person is going to fit in with the existing clients in that group house.

CHAIR - If someone is in hospital and they have had a traumatic event of some kind or developed a disease and they need further care, who makes the decision about which facility is contacted?

Ms WAGLAND - That is a nightmare, basically. Basically the social workers in the hospital have an understanding of what is available and what is not available, and they will ring around to the organisations. Unfortunately there are people who fall through the cracks. Mostly they are ones who have strong behavioural issues or mental health issues. They are always a real doozy group to be looking at - do they belong in the mental health sector, or do they belong in our sector? - but usually the social workers in the hospitals coordinate that kind of process and then will talk to us. We all talk to each other, and DSC also makes contact with us. They also have local area coordinators, who are like employed advocates through the Disability Services Commission and are area-based, and they provide services for individuals living in their own homes, but they also provide some back-up support for people who are at risk and don't have access to

accommodation or accommodation funding. And so sometimes we will get phone calls from the LACs as well, looking for support.

Mr WHITELEY - So it is a bit like in the hospital, which funeral director they ring? It is a bit of a lottery, is it?

Ms WAGLAND - Yes.

Ms HO - Also there are no beds anywhere, and so it is about who might have a bed. The client groups that don't get service at the moment are the 50+ stroke who can't return home, who need additional assistance; anyone with complex mental health issues, failed suicide, drug/alcohol confusional states. Ambulant confused young people have a real problem trying to be located anywhere, and tracheostomy clients. We have stopped taking tracheostomy clients because we can't manage the funding, and no one is taking them either, so they are blocking beds in public hospitals for up to 12 months.

Ms WAGLAND - They are our political football.

Mr MORRIS - I think we will find that if we look more closely it might be not that dissimilar for us.

Ms WAGLAND - But certainly we have by far the largest number of beds for people with an acquired brain injury or an acquired disability.

Mr MORRIS - We only have one specialist place for young people and it is a nursing home. The rest of it, as far as we know, are all scattered. They are either in the acute hospitals or they are scattered throughout the nursing homes in the State. We are just trying to get a picture of what is going on here. It sounds very interesting, although I must say that the funding model that is there sounds extremely complicated. Is that a drain on your resources, trying to keep track of all the money that is coming in and the restrictions on it?

Ms WAGLAND - It doesn't worry us, because the finance department has to worry about the money.

Mr MORRIS - As an organisation?

Ms WAGLAND - As an organisation it is quite complex, because we are answering to the Health department, the Commonwealth Government and the State Government, but we are fairly clear. I know they have a separate contract that gets renegotiated for the special needs beds with the State Government, and I think that is due to happen at the moment as to how that money is utilised, the number of residents they care for under that. We also have separate contracts with the Disability Services Commission, and our one with DSC has just been signed. We also have a separate contract with the Health department for our respite beds and for TRP, and that all gets renegotiated, and we get involved in those negotiations according to how it affects each of our facilities. So certainly the fact that we are answering to a number of different masters is difficult.

The other difficulty we have is that both Endeavour and Ellison House are not only DSC-funded, so therefore we have to undergo the standards monitoring processes and the

assessment processes that are attached to being a DSC-funded facility, but they are also classified as State Government nursing homes, so then we also have to go through the accreditation process of the Health department, which has expectations that are not totally the same as DSC. So we have to juggle what we present and how we talk to them, and the language changes, I guess, from one to the other, because one is more health oriented and the other one is more disability oriented, and they are very different.

Mr WHITELEY - Can I just ask for a break-up? You have here in your promotional material 700 residents and 18 facilities. I certainly don't want to waste time, but it would be helpful for us to know what service each of these facilities provides.

Ms WAGLAND - Okay. Balcatta is a facility that is 12 beds and is one of our community house accommodation facilities; Young People in Nursing Homes for 12 people with an acquired brain injury. Biralee is just a standard nursing home with 62 beds, I think. Edgewater is an aged care hostel. I am not sure how many beds, about 30 I think, so it is low care. Ellison House is a 12-bed community house for people with Huntington's disease. Huntingdale is also an aged-care, low-care facility. Joondalup is an aged-care, low-care facility. I think it is only about 20 beds, it is not very large. Kingsley has just converted to care-awaiting-placement, so they provide 44 beds for people in the aged sector who are awaiting placement in -

Mr WHITELEY - In one of the others?

Ms WAGLAND - Either ours or any other nursing home in the State.

Mr WHITELEY - A transitional place.

Ms WAGLAND - That's right, and it has only just started up. Manning is an eight-bed facility for people with an acquired brain injury, a community house. Marangaroo is this facility which has the transitional rehabilitation unit and Endeavour House. Endeavour is 18 beds, permanent accommodation for people with an acquired brain injury, and then you have your three beds that are privately funded, and ten beds that are rehabilitation. Maylands is a six-bed community house for people with an acquired brain injury. You are going to see all of the young facilities.

Mr WHITELEY - Just for the record, how does a six or eight-bed community home actually work on the ground? What sort of ratio of care et cetera?

Ms WAGLAND - Maylands and Manning both run two, two and one; two on a morning shift, two on the afternoon shift, so you basically have two staff from 7 a.m. to 9 p.m., plus one night carer. They both have ENs in the morning and afternoon on the majority of days - enrolled nurse and carer. Manning has a full-time therapy assistant who works 9 a.m. to 5 p.m. Monday to Friday, and think there are about 27 hours a week of therapy assistant over at Maylands, so they are very similar.

Mr WHITELEY - They are a group home? They are not individual units?

Ms WAGLAND - They are group houses. Manning is a duplex with four and four, with the accommodation for the residents, and Maylands has three people in the front house and three people in the back house, but they are very different configurations. The houses

are totally different designs according to the residents. They both also have physio, speech and OT and social work input of varying hours, so they are very similar but the residents have very different levels of functioning. Oats Street is a 24-bed rehabilitation facility, or it is actually a 24-lace, and I can explain that a bit later when we get closer to Oats Street. It is a bit complex. Onslow Gardens is a 62-bed special needs nursing home in the Subiaco area. Oxford Gardens is also a 62-bed special needs facility and it is in the Joondalup area.

CHAIR - When you say special needs, what kind?

Ms WAGLAND - They are high care, aged care, so it gets level 1 on the RCS plus, basically. They are people who maybe have gastrostomy feeds, high behavioural problems, specialised health needs like severe diabetes or something like that. They are people that other nursing homes cannot afford to accommodate because of those extra needs. They need a bit more funding on top of the standard Commonwealth funding.

CHAIR - Is there a specialised Alzheimer's or dementia area?

Ms WAGLAND - Redcliffe is a hostel, so once again a low care facility. Southlakes is also a low care facility. The Oaks is another 62-bed special needs accommodation facility. The Village I think is a 63-bed special needs facility, but for people who require a secure environment and have dementia, so all of those residents are mobile. Warnboro is a 12-bed facility for people with an acquired brain injury. It is a community house. And on top of that we now have Madderly, which is about a 110-bed facility, and part of it is low care and part is high care, all on the one facility.

Ms HO - And it has a locked dementia-specific facility as well, and it is also on the same site with Brightwater's first retirement village.

Mr MORRIS - Right. So it is ageing-in-place type stuff?

Ms HO - Yes.

Ms WAGLAND - So we have retirement village, then hostel care and then nursing home care all on the one site, and it is huge. We are just building a similar sort of facility that will have capacity for residents to buy in extra services, which is a new thing for us to do as well, down at Mandurah, so we are spreading further south. Joondalup is about as far north as we can go. We are starting to go south.

Mr WHITELEY - Can I just get onto again a little bit of the history of Brightwater? What percentage of care would you provide in the State? Obviously you are not the only people.

Ms WAGLAND - Ten per cent of the aged care facility, I think it was, and I think it is only 2 per cent or so of the hostel care, but it is still a fairly large proportion. For young people in nursing homes, the acquired brain injury group, we would probably have about 80 to 90 per cent of that group. Huntington's, 100 per cent, and apart from those who end up in nursing home care because they cannot get facilities, and even our existing special needs nursing homes will take on people with Huntington's disease. Yes, so that

is probably close to the percentage, plus a fairly substantial number of the aged care, at-home services packages as well.

Mr WHITELEY - You were just talking about what you do differently. What was that all about?

Ms HO - One of the things I said is we've built some very small units which are only eight or 12 beds. I don't think that we would do those as stand alone facilities again. We'd probably cluster three or four on a property so that we can use cheaper staffing models and keep our site-based overheads down and we certainly would design our buildings differently to how we've done it this time, building in more flexibility to how rooms can be used and which type of clients can be grouped together.

Ms RITCHIE - Can we get some more information about staffing models for cluster homes?

Ms WAGLAND - They vary for each one. I think when we looked at grouping people we would look very carefully at the staffing models and the amount of people that you can manage to accommodate for a certain level of funding. Depending on their level of need it would vary enormously. Somewhere like Manning has nowhere near the problems with its budget, its finance, because the residents are much more independent. So the actual hands-on staffing doesn't need to be as great as opposed to here where the hands-on staffing needs to be a lot more. Ironically, when DSC first funded us they couldn't get a handle on that and they provided this facility with less per head funding than they did for somewhere like Manning. But it needs to be reversed. The people who need the higher hands-on care need a much higher level of funding as opposed to the ones who have the regular community access. You can provide that by utilising existing facilities and other agencies that are already set up. We can transport someone there and there's already someone there to care for them as opposed to here, where if we take someone out in the community they have to have a one-to-one carer with them as well. So very different, depending on each group. Certainly Maylands and Manning have a very low staffing model. Maylands just manages the budget on a yearly basis and it has the same staffing model as Manning but only has six residents. But one of those residents at the moment has a gastrostomy feed. So we do have someone with that high care need, but with a much higher level of cognition, so much more able to understand what's going on around him. So he is someone who is very difficult. He has high physical needs but also needs a lot of stimulation and a lot of access to community things and activity in the house. So there's a mid range of functioning in that group compared to the guys here who need a lot of input for stimulation and hands-on care. So it's really different.

Balcatta and Warnboro are very similar but they're two totally different buildings. You won't see Warnboro but it's a duplex, even though it's 12 beds, so we have six and six in the houses. And that was because we had people who were very high care need purely because we were trying to provide a location that was closer to the southern area of Perth for people who lived in Bunbury, Mandurah, Rockingham. We accepted people who were probably much higher in care needs than we would normally put in a community house. To do that we did the duplex so that we could consolidate the staffing at any given time of the day depending on what the needs were. So in one house, the residents have more community access, so they have community-access need. The other house

needs everyone on the floor for meal times and getting them up and dressed in the morning.

Mr WHITELEY - Has that worked?

Ms WAGLAND - To some extent. I think it probably needs a bit more refining and I think we've found that that over the last two years. We've done a lot of restructuring and refining of the models and a lot of learning ourselves. I think Warnboro still needs a bit more refining but certainly it gives us a lot more. Basically, if you need supervision of the residents you only need two staff members, one in each house, if that's all you're providing. Whereas, for somewhere like Balcatta, which is three houses, you always need three to provide that. So it's that kind of difference in the flexibility of what you do. However, it's not necessarily seen as a traditionally home-like environment, having six people in one house. And you have to have things like an extremely large kitchen or family room area to accommodate them all. There are a lot of electric wheelchairs down there and a lot of large, tilt, recline-type of chairs. So to be able to accommodate that everything has to be big. And also you have to try to give the presentation that you don't have this huge facility with six bedrooms coming off this big area. So that had to be fairly sensitive in the design features as well. So it was unusual. I don't think ministry of housing would ever build it again because they like little nice, neat, three or four bedroom units. But we think it's workable if you run it properly.

Mr MORRIS - So it changes the nature of the game really? It's a lot of learning, a lot of change going on all the time.

Ms WAGLAND - And every time you change one resident you generally have to change your model of care again because it sets up different group dynamics and different activity programs or outside access that they're having here. I think you would find that here as well. You only have to have one heavier person come in and it changes the staffing, or a lighter person and you change it again.

Mr WHITELEY - With all the properties or the facilities you run, do you have floor maps of each of those as far as the actual design? You talked a lot about the importance of design. Do you have any?

Ms WAGLAND - Yes, I do.

Mr WHITELEY - My next question was to do with visitation. In a place like where we are now, how does it work with families that might be travelling a distance? Do you have somewhere that they can stay or do the residents have a room big enough that parents could bunk down for a weekend?

Ms HO - On this site we don't have a facility. But we are in the club house now and the lounge room can be closed off and I do have access to a fold-a-bed or something. If someone was seriously ill or something we could set something up. Routinely, our families just visit in the normal sense. A lot of our rehabilitation families have children and there is a lot of social activities so that's what this area is specifically for. When you have a large group of people you can come in here and have a party. Some of our married couples, where one of the partners is in, will bring in a meal and have a private meal in this area at night. We have TV and video in this area so they can bring in a

video. If the grandchildren come there's space for them to run amok without bothering other people. We have barbecues on site and families are welcome to bring in their sausages and have a family barbecue or something like that.

Mr WHITELEY - Is that something that has become a part of the culture here, part of the family?

Ms HO - It's interesting, in the rehabilitation clients definitely. But with the clients in Endeavour House, because they have been injured for many years, these are people who have had a head injury at 18 and are now 40 years old - their families are getting older. Their actual ability to visit is reduced and their wish to visit a person who doesn't respond has declined. It's very difficult to go in and hold a conversation with someone who can't speak to you and doesn't even acknowledge your presence. So we have found that the families have drifted off and they're quite happy with what we do and so they very rarely want to interact with us because they are frequently revisiting what is a very painful experience for them. So they tend not to want to come and discuss the client's care unless they have a concern. They've been through the process for a number of years. They are happy with what we are doing and so they just pop in occasionally. So we don't have lot of visitors in that client group.

Whereas at Balcatta, which is a community group home, we have regular social events. Last Sunday we had what we called the 'winter warmer' and all the families brought in a casserole and we all came together and swapped recipes and had a nice Sunday afternoon lunch. Staff sat down with the family and we all worked together as a group. They are working on their Christmas function this year, so they're all going out to a five-star event for Christmas this year because it will five years since they moved to the facility. So we're getting all the guys done up in black tie and stuff for Christmas. It's going to be a major logistic event. Whereas, normally Christmas would be a barbecue in-house or perhaps some Carol singing and those types of things. Each unit seems to have a different culture according to who the families are and the staff mix and so forth.

Ms PENNY BIRD, DIRECTOR OF SERVICE PURCHASING AND DEVELOPMENT; **Mr DAVID HOUNSOME**, MANAGER STRATEGIC POLICY; **Ms JUDITH CHERNYSH**, PRINCIPAL POLICY AND PROGRAM OFFICER; **Ms JENNY PERKINS**, DIRECTOR OF POLICY PLANNING AND INFORMATION; **Ms ROSEMARY LAWN**, POLICY OFFICER; AND **Dr RUTH SHEAN**, DIRECTOR-GENERAL, DISABILITY SERVICES COMMISSION, WERE CALLED AND EXAMINED.

Ms BIRD - I'm Penny Bird, Director of Service Purchasing and Development within the commission and it's our directorate that manages the contracts with all the service providers and the quality assurance of those processes and so on.

Mr HOUNSOME - I'm David Hounsome, Manager of Strategic Policy and I have been with the commission since 1980.

Ms CHERNYSH - I'm Judith Chernysh, one of the principal policy and program officers and I have carriage for young people in nursing homes, that policy portfolio area.

Ms PERKINS - I'm Jenny Perkins, Director of Policy Planning and Information. I will only be here for about 15 minutes because I have another appointment but David will be covering our policy perspective.

Ms LAWN - I'm Rosemary Lawn, a policy officer and I work with Judith and David. I am here more as an observer.

Ms CHERNYSH - I will make a number of documents available to you. One of the sets of documents relates to the history of our young people in nursing homes. It documents its origins and also the early stages of the development of the options for the people who are eventually provided with services through this program.

As I understand it, David and Jenny and others are invited to make comments.

This program had its origins in part - there were a number of things that were happening back in 1995. There was the need to rationalise nursing home beds. We had a dual system where we had State Government involved in the provision of aged care nursing homes and we had the Commonwealth also involved in that. Around that time there were discussions around trying to rationalise the provision of nursing home beds and that included also beds that were in the disability sector. We also had an inquiry into people with an acquired brain injury and their accommodation support needs.

This is Dr Ruth Shean, the chief executive officer or now Director-General of the Disability Services Commission.

Lin, it might be worthwhile again explaining who you are and why you are here.

CHAIR - We are half of an eight-member standing committee of the Tasmanian Parliament Made up of four members from the upper House, four from the lower house and across the political spectrum, so Liberal, Labor, Independent and Greens. We receive references on a variety of community development-related issues and the most recent is

looking at the provision of appropriate accommodation for young people with disabilities who tend to currently live in nursing homes in Tasmania. and looking at alternative provision.

The end product of our work will be a report with recommendations to State Government.

We are here because we have heard wonderful things about what you are doing here.

Ms CHERNYSH - We are just starting at the history and talking about the antecedence to our young kids in the nursing homes which had to do with the need to rationalise the aged care sector. As well, we have an inquiry into people with an acquired brain injury and their accommodation needs and the recognition that more appropriate response is needed to be made to address that group's needs.

We also have the first Commonwealth/State disability agreement being negotiated. So there were a number of things that were happening and people saw it as a time perhaps to address the need of young people who are inappropriately placed in State government aged care nursing homes.

That is the impetus for what we have. We got agreement from the Commonwealth that beds would be closed in State government licensed nursing home sector and that some of the money would flow from that to enable us to set up or for the provision of alternative accommodation and support options. In addition to that, we got the Health department as well to agree to the provision of funding for this.

Ninety-five beds were identified in Mount Henry hospital and in the Brightwater Care Group which was then known as the Homes of Peace. They were a provider of nursing home services. Ninety-five beds were identified with 95 people in them who, it was felt, could be better supported outside of an aged care facility.

CHAIR - Did that require you doing an audit of exactly who was who?

Ms CHERNYSH - I think the health department may have done an audit identifying people. I would have to go back and look at the documents but I believe they did an audit, looking at who might be appropriate to consider for this particular project.

Ms PERKINS - It coincided with the Mount Henry nursing home, which was a State government-funded nursing home that was being closed and relocated so they had to do basically planning for all people resident in that facility, which included them identifying this population.

Ms CHERNYSH - So once there was agreement about that, a project team was established to then look at the development of options for those people and these three volumes document that work that was done.

There were a number of providers who were identified as probably being the providers who would provide accommodation support services, Brightwater being the biggest because it had the most people who were in nursing homes. The Multiple Sclerosis Society was another provider that was identified, the Cerebral Palsy Association was

another one and there were three individual options as well where in some cases people negotiated with an individual agency to provide them with support whereas others went into group homes or more congregate types of care.

Mr HOUNSOME - What was remarkable for the time and for the population was that it was an individually planned service even though many of them were in congregate options. The start was talking to the individual, talking to their family, looking at their needs, looking at where they wanted to be relocated to geographically and in terms of service model, which included the transfer to another nursing home or a move to whatever because there could be bed substitution for persons. That I think for that population at the time seemed to be quite remarkable. It is standard practice now but it would have been very easy to have said that people of this need a profile. We should be building x number of group homes and asking them which suburbs to put them in but that wasn't the case.

CHAIR - It was right down to what people wanted.

Mr HOUNSOME - Yes, there was consultation in every single case with families and with individuals.

CHAIR - Do you have any way of identifying the likely need into the future? Is it possible at all to track into the future needs?

Ms CHERNYSH - We are currently wanting to take a closer look at this population. At the moment we have the young people and nursing home program. That currently supports 86 people at this point in time and it can, when vacancies occur, be made available to people who are currently in nursing homes or at risk of entry to nursing homes.

The program, the way it is presently constituted, serves people with acquired brain injury, people with Huntington's and people with multiple sclerosis. Those are the three groups and those are the three groups we targeted initially when the project was originally set up.

As you may be aware, the Commonwealth Government is increasingly wanting the States to address this issue and to provide a more appropriate response for younger people who are in nursing homes. One of the issues for us is to ensure that we clearly identify who these people might be - the ones perhaps who are currently in nursing homes or at risk of nursing homes and to look at the degree to which we can support them.

The program is unusual in that it provides for a range of needs across both nursing and disability. That program is a quarantine program within our overall programs of disability support and funding because we do not normally provide nursing care especially through the funding that is currently being made available to people who apply for accommodation support. So it is not something that we ordinarily do but through our YPNI program we have the capacity but the vacancies are only one to two a year and the number of people are certainly far in excess who are going into nursing homes than what we have available to cater for.

There would have to be an expansion within disability support funding and there would need to be some acknowledgement of the need for funding with respect to health care and medical nursing care-type needs.

Ms THORP - Is that basically a political decision, a funding decision?

Dr SHEAN - Can I just say that I am not sure that we are looking at vast numbers of people being appropriately placed, Judith.

Ms CHERNYSH - We only have two vacancies a year. Even if there are 30 people we can't accommodate.

Dr SHEAN - The reality though of some of the people who were in nursing homes before was that they didn't require nursing care and they were the people who were targeted by the Young People in Nursing Homes Project.

So many of them moved out into - and I was involved as a service provider from another agency's perspective when this happened. Many of them moved into non-nursing options and I presume they are the positions that remain such as the CPA ones. Are they still quarantined as younger?

So they are not all nursing placements, which needs to be made clear.

Also, it's now much harder for people to get into nursing homes so unless you meet the ACAT requirements, the likelihood of you getting a nursing home position inappropriately is probably quite low.

A lot of people who go into nursing homes are there for probably good reason - people who maybe are HIV positive and have full-blown AIDS, for example, people with MS who are in the final stages of their condition and really do require nursing care and may not be inappropriately placed. Another group that we are aware of are people with psychiatric conditions who are a health-based group.

We do have nursing facilities - not part of the Young People in Nursing Homes Project - that we fund in disability and some with quite good high levels of nursing support. We have a couple of high support needs hostels of our own and in the non-government sector, Penny, there are still a couple of licensed nursing homes or at least that provide some nursing care.

It is not just limited to the Young People in Nursing Homes Project and I think to give you the impression that we had done this once but the problem was now growing again would be to mislead you -

CHAIR - Yes.

Dr SHEAN - because I think there was a backlog element of this clearing people who were inappropriately placed.

CHAIR - Which will be the experience we'll have, should we move in this direction. There will be a pool of people who will need to be re-housed more appropriately and then a

steady stream thereafter, I suppose, of people needing to change or coming from home for the first time as time goes on.

Ms BIRD - I don't think we do have good predictors of the number of people, just as it's very hard for us to get a handle on predictions in terms of accommodation support and demand overall. It would be very hard for us to say our normal accommodation support - the profile of those people - if they did not receive disability funding, where would they go?

In the past they would have all gone into nursing homes because that was where everybody went. Now with a very strong disability accommodation support program most people don't go that route. Most people who go that route are those who are indeed in need of that kind of care and in terms of a person with disability ageing they are more commensurate with that age group as well.

There are certainly still some, but it is a small number of people who because of the lack of accommodation support funding there is simply nowhere for them to go. They are generally people who are in hospital already for one reason or another. They will stay within the health system and then usually aged care residential facilities. They are the people who our primary concern is for, going into young people nursing home beds.

Ms CHERNYSH - It is not a simple picture that it's across all States. You are right in thinking we are dealing partly in some situations with a historical-based population who, for whatever reason, have gone into nursing homes.

Western Australia's experience, I guess, is that with the one project that we have had it has probably made a significant impact in terms of that historical population.

We now have in place, although there remains unmet demand across all of our accommodation support funding, we have had significant sustained growth over the last five to six years in terms of accommodation and support funding which, I would suggest, has had an impact in terms of the pathways that people may have otherwise gone. The numbers have been much lower in terms of people who may have entered nursing homes.

There is a difference in being a very large State having particular issues for people in rural and remote areas. There will be a small proportion of the younger people in nursing homes who we have identified who are in regional areas where there are real gaps across health and disability in terms of the service provider capacity. In many situations you will find people have chosen to go into that type of accommodation if the other option is for them to move into more age-appropriate accommodation in an area that is outside their locality. So that is a very specific issue which possibly Tasmania doesn't face.

CHAIR - We do because we are very dispersed.

Ms CHERNYSH - True, but not so in the long distances.

I think that is why for us the work that we are hoping to do as a national research project through the national disabilities administrators is to get a better picture of who is in

nursing homes. For me they are interesting issues to ask in terms of what are their support profiles and the length of time people have been in nursing homes. I think it will be different to see whether you are talking about basically a longer-term cohort versus more recent entries because there certainly has been a change in terms of what the access pathways are for people seeking nursing home accommodation with the tightening up of your ACAT criteria. Previously people may have made decisions which now no longer are there as options.

One of the challenging things I think for all of us from a policy point of view is this question of appropriateness. I think that is not so much an emotive word but how do you define that? I think that is going to be a real issue for all of us across many sectors to try to work out. Certainly to assume when you look at the numbers that all those translate to people who should not be in that setting is not right.

Ms BIRD - In the same way, Jenny, one of the difficulties even across government is, if you go through that layering effect, of saying this group is inappropriately placed in a nursing home. That is a very overt, in-your-face group. It can be very difficult then to balance the needs of that group and the people who are inappropriately remaining within their family home and who haven't gone into a nursing home.

When we look at accommodation support funding, that is one of the challenges for us to be able to find, that if you do sectionalise your target group then how do you keep equity between the different sections. That was a big challenge for us in going down the path of quarantining young people in nursing home beds because the moment our accommodation support funding is allocated to those in most relative need to each other it is difficult to be able to then say that the beds for young people in nursing homes are those most in need of a bed, because they may not be.

So the appropriateness doesn't just relate to people who are in nursing homes. There are people who may well be inappropriately supported in a number of settings. Trying to ensure principles of equity are maintained across different populations and different sectional interests is one of the most challenging things that we have.

Dr SHEAN - Maybe this is more of a personal observation but I think it has a big impact under Commonwealth/State interface with regard to - you've got to realise that also nursing homes have evolved themselves and have changed quite significantly over the last decade or so with the Commonwealth approach in terms of the their focus. They are now called aged care nursing homes. That is new. The age profile in those nursing homes is changing significantly as aged care policies have changed and the understanding of seeing what is appropriate from an aged care perspective.

I find that that is not put on the table a lot in terms of some of these discussions, and in many ways you can understand why not because it is secondary to the issue that you have, is profile of young people in these settings. Historically it has been more appropriate for people with certain levels of support needs which fit those criteria. That is in the past where that level of support has been provided. So it is only in one way a recent phenomenon because aged care themselves are now changing their definition, which has been placing enormous pressure from a disability perspective, and it has enormous funding implications.

CHAIR - What would be the process if I was a parent of a 20-year-old young man who broke his back surfing, for example, and our life changed radically in that he was never going to walk again? As a parent I would probably be in the acute care setting to this point. Where do I go? What happens then? Who looks after him?

Ms BIRD - The social worker generally at the hospital is fully aware of the application processes of funding for disability because a 20 year old with spinal cord injury would be seen as in need of disability support and the social worker would assist the person to make contact with the potential service providers in that area.

In Perth, the spinal cord injury unit is on the same grounds as the association that supports people with spinal cord injury so they will have already had a connection with that particular service provider while they are an inpatient. It is one of the services that they offer.

There are other service providers and they would be providing information about them. They would also have access to local area coordinators so the social worker may or may not make contact with them and the local area coordinator can particularly inform them of other support options available through service providers.

The first step would be to put in a funding application for accommodation support and that application could be for out-of-home accommodation, which is what our accommodation support funding is, or for intensive family support, which is support in the family home if they were returning to the family home.

In either case, the support needs would be assessed around what supports the person has in their community - from their family, other sorts of support and what are the gaps. Depending on the relative need of that individual in any particular funding round, and funding rounds are three times a year, that person would be funded or not. If they are not funded they tend to stay in an acute setting until the next round and so on.

Ms CHERNYSH - They could apply to the quadriplegic centre as well, couldn't they - someone with a spinal cord injury?

Ms BIRD - They can't apply to the quad centre per se, no. They would need to come through CAP and that would be allocated through CAP.

Ms CHERNYSH - Okay, I didn't realise that.

CHAIR - Say if the funding was provided through that funding round, would it be then a matter of finding a vacancy in an appropriate -

Ms BIRD - No, no that funding would create a new service for the person.

CHAIR - Okay.

Ms BIRD - If what they wanted was some shared care with some other people it may well be a case of looking at whether there is an opportunity in a home somewhere where there are compatible other people, although that is very rare for spinal cord injury people. They do not normally choose that. They usually choose to be independent or perhaps

share with another person or in a duplex unit type arrangement where they may share some of the care but not share their living arrangements.

What we would call individual options is typically what someone with spinal cord injury would have.

Certainly for someone with acquired brain injury the profile would be quite different. They frequently do seek shared care because of the additional supervision and 24-hour care that they need.

CHAIR - So do you have a situation then in your hospitals where there are people staying in hospital longer than they would but for funding issues?

Ms BIRD - Occasionally. It is not a large number. We normally know about all of them. The hospitals are pretty quick to let us know and at this point in time I guess I would be right in saying there are only about two that I know of that I can think of in this round who are in hospital.

CHAIR - It is not strictly related but do you have an issue with older people who need to go into an aged-care nursing home staying in a hospital setting too? Do you have an issue with that?

Ms BIRD - Yes, we do.

I don't think it is huge though. There are step-down facilities within the hospitals. There are beds called 'care-awaiting-placement' beds and there are a number of those where people go out of acute hospital settings to more supported but less intensive care arrangements while families determine which nursing home they are keen on or which hostel or which aged care residential facility they want. Then there is a waiting period usually and that is very idiosyncratic as to how long and whether or not you take the first vacancy or whether you wait for the vacancy of your choice.

Dr SHEAN - There is a problem with people with disabilities waiting for nursing home placements but where the wait would be in their own dwelling or in a different sort of facility.

A few agencies have approached us and we have had similar problems in our services where people have had an ACAT assessment, they are fully entitled to a Commonwealth-funded place but finding a place for them to go is difficult or they have gone into a nursing home and been evicted after a couple weeks. We did have one case where there was that problem, Penny, because of the behaviour they displayed. Nursing homes, by and large, feel they shouldn't have to take people with disabilities; they believe that is a disability issue.

One of our arguments is that there may be some people inappropriately placed in nursing homes but there are probably a larger number of people inappropriately placed in disability facilities because they cannot get into nursing homes.

One of the things we hope to be able to explore under the current Commonwealth, State and Territory disability agreement is just how best to improve the plights of both of those groups.

CHAIR - I have been monopolising that bit.

Mr WHITELEY - No, it's good because it localises the microphone; you're doing well.

Mr HOUNSOME - Some of that working cooperatively with the Australian Government might have a sharing of resources and services because we do have a policy of age in place and it is not as the other State wishes to pursue, that when you reach some age cut-off, the disability services would cease and the Australian Government aged-care services would start. There does need to be an acknowledgment that we would be providing services of increasing intensity that for all purposes, would be like aged-care purposes and that needs to be factored in.

Dr SHEAN - There are some funny little bits that get caught in the gaps and one of those that I have been directly involved with is the provision of equipment. If you are in a disability facility, equipment is the responsibility of the State and the processes for the allocation of that are centralised and very, very good. If you are in a Commonwealth facility such as a nursing home, the equipment is the responsibility of the Commonwealth and is probably of a very different nature in terms of its specification.

We have had a couple of complaints through the minister's office where there have been people not inappropriately placed in nursing homes but where they cannot get appropriate equipment.

There was a particular one which does not ever go away, where the woman is about 50 and I think there is an element of dementia in whatever her disability is. She is clearly a Commonwealth responsibility, no-one is arguing that, but she wants a power chair and she repeatedly goes to the minister's office saying she cannot get a power chair. The minister's office say to us they would like us to get a chair for this woman. When we investigate at the hospital the nursing home doesn't support it because they said that she is very high risk and will get herself run over if she is going out.

So, there are lots of issues around these little bits and pieces.

The State supports given to people in disability-funded accommodation are very different than if someone's in Commonwealth-funded accommodation, and this is a critical CSTDA issue that we have also agreed to look at. If for example, you are in a nursing home that is Commonwealth-funded, what if any is your entitlement to State-funded ancillary services? Equipment is probably the most obvious problematic one there.

Ms BIRD - I guess that is that bigger issue too of if you can agree when somebody is appropriately placed within a residential aged care facility versus a disability community-funded facility.

You have been to Brightwater. In some situations you cannot tell the difference between one and the other. They look precisely the same. Some of the more recently built Brightwater residential aged care facility ... (no tape overlap) ... so where those physical

facilities are really the same, it's easy for people to feel comfortable to move from one to the other. But when there is a major difference in the physical facilities being offered by a nursing home versus disability, often people advocate to stay in disability for much longer periods, and want nursing support beyond that which is possible for disability to have, purely because the design and the physical facilities being offered in residential aged care is inappropriate to people's needs. But it is to anyone's needs in contemporary society, it is not whether it is inappropriate to people with disabilities, it's for any aged person going into that facility. Sometimes I think the rights of everybody are being ignored in this whole debate.

Dr SHEAN - I think design has been significantly under considered in this debate generally, and I still get a little concerned about some of the developments that we are part of because I think there are design problems that are going to become apparent over time. The issues - and you'll see this when you go to the Maylands place - that people value in terms of their living space is you clearly want to have your own bedroom, and one of the problems with some nursing homes is that it's a ward-type accommodation, not your own room. You want to have your own bathroom, and increasingly new nursing homes are built with a bathroom per person. There's a new one that Paraquad have just built as an aged-care facility out in Bass and Dean, which is beautifully done and each person has a bedroom and their own bathroom, and it's an accessible bathroom.

Ms BIRD - They found that one bathroom per two rooms is the only economical way that they can build.

Dr SHEAN - The new one that was opened about a fortnight ago they've still stuck with one on one. But going back to the Maylands unit, the other thing that's really important for people is a sitting area of their own, too, and for people who have limited physical capacity but emotional and intellectual needs which are demanding, the Maylands option has come up with a couple of terrific options. There are some shared care or congregate care arrangements there, but there are some bedsits off the main centre, which I think make for quite economical care but give enormous privacy and a good dignity of lifestyle.

We've got quite a few that we are involved in through either our own services or funding of other services, and you are probably not seeing this because it's not a nursing home but there is a triplex development in Nollamara north of Perth run by an agency called Blue Sky. It's for three men with profound physical disabilities, but they all have their own units. They can all operate the front gate and they can see the front gate from their front rooms, and one of them operates the front gate with a foot control so he can let people in and out, as well as get in and out himself.

There's a carers unit on site, too, so there are three people. In fact there are now four, I think; there's a fourth one in that, Penny. He lives in the neighbourhood and also gets support. To all intents and purposes you have people there in individual options living on their own with their own lifestyles, but they're actually sharing their care among four people which reduces the costs enormously. And the Brightwater one that you will see does similarly, although in quite a complex configuration.

I do think that, getting back to Penny's point, it's less to do with who else might be at the facility and more to do with where it is that you are what your bit looks like. I don't

think it matters a great deal if a young person is in a nursing home, as long as the environment is appropriate; it's not in a ward with lots of elderly people where the only other people around are elderly. If a person needs nursing care, there is no reason why that cannot be provided in an appropriate setting, within a nursing home. Nursing homes do provide appropriate living environments for people, and there's nothing inherently bad with intergenerational mixing. There certainly with a predominance of one age group versus another, that's an issue. There are issues around stimulation and participation, and so on. So those are the issues rather than age that are determinants as to whether or not a living environment is appropriate or not.

CHAIR - Food, too.

Dr SHEAN - Well, presumably elderly people don't necessarily all want to eat the same thing. Choice of food is highly important regardless of what age you are, unless of course you're under two when you get no choice at all.

One of the things we found with the young people in nursing homes project is that there are a lot of people in that who did not need nursing care, and there were people who had gone into nursing homes because at the time there was clearly no other alternative. There were two that I knew very well who were quite elderly women - twins, I think they were - with intellectual disabilities, with no nursing needs at all. But they had gone into a nursing facility for some reason; they would be about 70, the two I'm talking about. One subsequently died, but they were in one of the mainland properties, the Kirkham Hill Terrace area or Watson Place. Probably when they were born and relinquished, there was no option other than the psychiatric institution that we had here, and their parents didn't want to do that, so they went into a nursing care sooner or later. I don't know at what age they did that.

Another one that I looked at lately is a Broome nursing home. There's an Aboriginal nursing home in Broome, primarily, I think, with Aboriginal men. When I was up there about a year ago, I went to see a young man who without doubt is inappropriately housed there. But it would not be appropriate, either, for us to offer him a congregate care setting, and there isn't one in Broome that we could use. But fortunately the nursing home itself is devolving to more appropriate accommodation, so we're not the only people trying to do the right thing here; others are doing the same thing. What they're going for, I think, is some sort of cluster housing where he would be living with people - and there are a handful of them who are younger - in fairly independent facilities.

CHAIR - Just talking amongst ourselves as we've gone from place to place, the consensus amongst us seems to be that we've got nothing in Tasmania really that is appropriate.

Dr SHEAN - Willow Court, you've had to wind down, of course.

CHAIR - So we'd be starting from scratch, really, which does have its advantages.

Dr SHEAN - Absolutely.

CHAIR - And we'd probably be looking at geographical situations with a whole variety of facilities provided, but separately, if you like. You might have one house between three

or four people with similar needs, and another house over here and another house over there.

Dr SHEAN - Or maybe people collocated in separate dwellings if that suits their needs. I think one of the things that did happen well here - and this was before I was with the commission - was looking at individual needs and that's something we always try to do in the current funding processes. Although there are some vacancies that go to people who are prepared to take them, by and large, people get the opportunity to design their own living arrangements if that's what they want.

Ms PERKINS - Another thing that is interesting is that at the time the parents of people in nursing homes were actually very anxious about them moving out of the nursing home. We're talking about how people don't want to move out of disability support, but there are a lot of families who actually perceive a nursing home as being the best level of care. I suppose the nursing home staff also have a vested interest in maintaining that. I think when you're looking at any transition, you'll need to think about that. When the people have moved, families were still very concerned about care as a theme, and that being met, whereas when you spoke to the people themselves, it was often about their quality of life. Care was important to them, but it was more about, 'I've got a better place to live, I can go out more, I've got privacy, I've got better food'. It was more that rights issue, but I think in moving a lot of people there will be real anxieties because parents often don't see, they can't visualise the transition, what's going to apply.

CHAIR - That's the same for parents, always, isn't it, when children make transitions. There's fear and nervousness and concern that they'll be all right.

Mr HOUNSOME - It was quite a feature of the people in nursing homes project, but it was true also with every major change the commission's made to its accommodation services. So when we wanted to close Kirkham and move people to situations that were much more appropriate and had many advantages, there was a clinging to the old model and what's known is most secure and best. The change of accommodation invokes all sorts of uncertainties and opens up the original decisions to actually have the person live outside the family home, anyway. I don't know of any major changes that haven't had some of those features of concern of families.

Ms BIRD - I would encourage you to look very carefully about what is appropriate for people, what is an appropriate placement for people in nursing arrangements where they genuinely need nursing care that is complex, extremely expensive and critical to their life wellbeing, compared to people who are absolutely able to live in the community and may well need a visiting nurse arrangement, or some contact with nursing care or carers trained. With our program at Silver Chain the nurses train the carers directly with that individual, and declare their competency around a procedure. All of those kinds of step-down nursing procedures are perfectly appropriate for the community, across all ages and across all groups.

So being really clear about when is it that you actually need highly complex nursing arrangements which, in our belief, would be something that's akin to residential aged care. In this State, that's the only place where you can get it versus community disability support where you can accommodate quite complex needs with challenging behaviour, complex needs in terms of ensuring a good, healthy lifestyle through appropriate access

to medical supports that are in the community. Once you sort those two out, then it shouldn't be a big deal about how you accommodate so-called young people in inappropriately placed aged-care residential facilities, because they are the same disability programs that everybody else accesses, and they should be indistinguishable between the two.

In that regard, all the principles that drive what makes good design around supporting people with disabilities in the community are the ones that you have to keep foremost in your mind. So are these individuals going to be living away from the family home versus in the family home? More than likely they're going to be out of the family home because of the history of where they're currently placed. If we're doing that, there is this issue of people probably requesting more support than they may ultimately need, and having some kind of strategy around that is important. Then I think for me, one of the most critical things to do is to get your environment right, which is what Ruth is saying.

We find, because I'm in service purchasing and development, the inflexibility of the traditional four-bed group home is really quite limiting, and certainly the bigger arrangements in terms of single dwellings make it very difficult for us to effectively manage and efficiently manage the provision of accommodation support. On the other hand, if you do get individual living correct within some shared care, you can get tremendous additional support for people that they don't otherwise get. And there is the flexibility of the staffing arrangements, so if you're constantly in one-to-one arrangements, you are very rigid about when the person's there, when they're not there, what they can do when they're there and what they're not versus some of the other arrangements where we've got some lovely complexes that actually end up with quite a number of people within a site, some of the active foundation ones. From the street frontage it looks perfectly like any other house, but there's another street here exactly the same, looks perfectly appropriate, but in between there's actually quite a lot of common living space very cleverly designed so there are a number of courtyards, not just one. Within that arrangement, the staff can share their supports across, according to criticality of need. There won't necessarily be a staff member in any one place; they may be both over here, or whatever.

The residents have found that that gives them the opportunity if they don't like a meal here, they pop over there because they like that one better. If somebody's showing a video over there, they might all go there, but the ones who don't want all the noise pop over here. Somebody here's going out on a bike ride, and a couple of them will go out on the bike ride. That kind of facilitation of relationships and social participation within that group is one of the significant benefits, and has contributed more to the acquisition of self-care skills and their own sense of wellbeing than anything else you could have delivered for them, but it's still done in a way where they have separate bedrooms. There is a separate lounge, dining room, and so on, so very individual and homely. That was very good for that group who do have intellectual disabilities, and for other people that we talked about earlier - spinal cord injury - cluster and unit living like the triplex, as Ruth was saying that often that provides a greater separation that some people are seeking. So there are different designs according to the characteristics and demands of different groups.

Mr WHITELEY - Obviously the bottom line, I suppose, in some cases is it's more affordable, too.

Ms BIRD - Absolutely. That one that I was just talking about was actually a devolution from a very large, old-fashioned complex, too, to more modern arrangements, and they were able to accommodate more people, not less.

Ms PERKINS - We often think about the accommodation, but there's also what people do and how they get out of their accommodation, which I think was a problem, wasn't it. It was a bit of an afterthought, and I know a lot of people within the CPA homes were, 'How do we get out of here during the day?' Yes, they probably should have been getting out of the nursing homes as well, but then it was because of the awareness of the service provider, their quality of life, so that was another issue that you really need to think about.

One person who really wanted an individual option was living in Rockingham. She has MS. She ended up, because of not being in a cluster, being incredibly isolated in that individual option. That was what she wanted to do, but there are those issues of interaction that you were describing as some of the real benefits.

Dr SHEAN - I think you want to be careful that there's no one-size-fits-all, and going back to my earlier comments, too, just because you do have your own bedroom and your own bathroom and your own sitting room doesn't mean that you are necessarily living the life that you want to live. There are some congregate-care facilities where people are sharing and it works incredibly well. One of the problems with congregate-care facilities is that vacancy management, which is critically important to good service delivery, becomes very complex. Compatibility is a huge issue. There are two stumbling blocks for us in terms of providing accommodation: one is the money, but the other is the vacancy itself or the option in getting that up and running. Compatibility can be a critical issue in that, so it's not a question is simply getting four people together with similar needs and putting them together because they may not want to be together.

Mr WHITELEY - We can take a stable environment, insert one individual amongst four or six, and upset the whole thing for the next twelve months.

Ms BIRD - And we do that so often.

Mr WHITELEY - And the energy and staff time it must take to fix that.

Ms BIRD - We don't find that similar support needs is a good predictor of compatibility, nor efficient design, either. Often diversity of need is actually a better outcome for people in terms of good use of resources, but again that's not a rule, it just does seem to depend on the creativity of the service provider, their knowledge and understanding of the people they're working with, and their capacity to make things work. It's a very human-based response, as well as a -

Mr WHITELEY - What is a good model then for assessment?

Dr SHEAN - I think nothing beats talking to the person, getting them to have a look around or their family to have a look around, spending a lot of time getting to know what they need. I think letting people, to some degree, determine what they want, and the problem then is getting a realistic view of what can be afforded, too, because if we say to people, 'We'll fund what you want', we'd fund a fraction of the people that we manage to fund.

So we've got benchmarks which say, 'This is the level of funding that you're entitled to', and then seeing what they want. Penny actually has a number of staff whose job it is to try to facilitate happy combinations, and you've had some terrific success on this, Penny. How many did Ken place last year, in terms of -

Ms BIRD - Eighty-seven, I think.

Dr SHEAN - Just a lot of combinations of people where someone's really unhappy and wants to move, somebody else will actually be quite happy to take their place.

Mr MORRIS - So it's flexibility and swapping.

Dr SHEAN - Yes, and someone knowing what's going on, too. You do need someone who is managing the service. We used to have a list that we called the multiagency placement service for people who were unhappy and wanted to move. All it was, was a list of people who were unhappy and wanted to move. Penny started managing that a couple of years ago, and we've now got a terrific success rate of helping people to move. This by and large compatibility is one of the critical issues here.

Mr HOUNSOME - One of the things that we have in our system that does help bring some order to it is an instrument that allows us to assess the support needs of individuals, and then base the resourcing limit upon that instrument which is very well validated.

Mr WHITELEY - Who developed that instrument?

Mr HOUNSOME - We developed that here in Western Australia.

Ms BIRD - There is a national project being done. The NDA is looking at what would be a resource allocation tool. That's going to be a couple of years' project certainly at this stage. We're just putting out a tender now, it's in the press, looking at what is the framework, so how do we describe what we're talking about in terms of assessing need, assessing prioritisation for allocating funding, assessing funding. There's a whole range of parameters when people just talk loosely around some of these things. We actually want to get a common definition, a common understanding and a framework that we can nationally live with and then within that look at what are the tools that you need. A tool for us assessing support needs is different from a tool for costing benchmarks is different from a tool - we do have a prioritisation tool, so all of those are different as well.

Mr WHITELEY - So the instrument you were referring to was in what area?

Ms BIRD - A support needs assessment tool.

Mr WHITELEY - Is that a top-secret instrument, patented?

Mr HOUNSOME - It is, yes, because you can actually rig results or assessments in order to maximise your dollars. It occurred in an environment where there were questions being asked about some people have a per capita cost of \$15 000 a year, and we have others that have \$115 000 a year, and there were people not being able to differentiate between individual support needs and what were efficient service providers and inefficient service providers, which meant you picked the lowest per capita cost and said that's where the service should go. That would have been a disaster to the whole of the sector.

What we did was study 600 individuals in a wide range of circumstances where we were happy with the quality of the service, and we measured the likely support needs characteristics. There are about 32 of those. Then, using regression analysis, we were able to explain and we measured how much time people needed in support intensively every quarter of an hour over a two-week period. We kept diaries on all of that, and we used regression factors to be able to study which factors were the ones that explained the high use or low use of time.

Then we did a secondary analysis to say that when you put those people together, when you have four of them live together, what would be the combinations that would best explain why some places need 100 hours of staff per week and others need 20 hours of staff per week. It is a combination of presence of challenging behaviour. Quite clearly there's a cluster of things around self-care in dressing, washing, feeding - they're all highly correlated. There are a number of key factors and the presence of those requires more or less staff. But it is purely to work out in a given service system which individuals should get what share of resources; it's not to do with what kind of services you need. That's a secondary matter.

Ms BIRD - With the support needs, it is a confidential tool. We will share it and we have shared it with others, but only on the basis that you retain the confidentiality of the scoring and that you don't give it to anybody else. So it is a possibility. That's called the Ursee, that instrument, and we are currently looking at the Icap as well. So we're collecting Ursees and Icaps on all the people that we. It is an inventory care assessment profile - something like that. It's an American tool, and it has some very American language which is unacceptable to us, and various things like that, but it is internationally validated and it is a very reliable, robust tool. So we're collecting Ursees and Icaps on all the people that we provide accommodation to. We're just going to see if there are any correlations between the two. We are also speaking with Queensland, New South Wales and South Australia to see whether or not they're interested in collecting data - Icaps - on their populations as well to see whether we can get some more robust data. We don't know what's going to come out of that, but given that we have the Ursee, it's going to be interesting to compare it to the Icap. The reason we want to do that is that the Ursee was developed on 600 individuals who predominantly had intellectual disability, it's not a good predictor for some groups of people. At the moment we don't have a tool that covers everybody, although it covers the majority.

Mr HOUNSOME - One of the things you have to be wary of in developing such tools of course is that you can actually afford to implement them. If you develop it completely outside of your current resource base and then apply it and say you're guaranteed this number of hours, so when we developed the Ursee we used the same methodology really that the Australian Government used to develop the RCS, the Residential Care Scale, in that we took the total quantum of hours in the service system and then we were able to rationally distribute that. We did make sure that all of our units operated broadly within their Ursees scores, but we were able to do that because we took into account the quantum of resources we had.

Mr WHITELEY - So you worked to an end?

Mr HOUNSOME - Yes, that's right - which is quite an important point.