

THE PARLIAMENTARY JOINT STANDING COMMITTEE ON COMMUNITY DEVELOPMENT MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART ON TUESDAY 28 SEPTEMBER 2004.

INQUIRY INTO YOUNG PEOPLE WITH ACQUIRED DISABILITIES

MS INGRID GANLEY, CO-ORDINATOR, STRATEGIC PROJECTS AND **MS ANNIE CURTIS**, SENIOR PROJECT OFFICER, STRATEGIC PLANNING AND DEVELOPMENT, DISABILITY SERVICES COMMUNITY SUPPORT DIVISION WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR - Thank you both for making yourselves available today. As you would be well aware, the reference that the committee currently has before it was stimulated by the interest of Mr Morris and Mr Sturges some time ago. What we are trying to do is ascertain what is going on for young people in Tasmania when they need a high level of residential care; what kind of numbers we are looking at and what kind of strategies are in place to make sure that that accommodation is the most appropriate. If you could just let us know where you come from and talk us through what is happening in Tasmania, that would be really useful.

Ms GANLEY - Both Annie and I are from Disability Services in the Strategic Planning and Development Unit. We are both involved with projects looking at younger people with disabilities in nursing homes, as well as the aged care issue at the same time.

By way of a bit of background, as of March 2004 there were 23 people aged under 50 who were accommodated in an aged care facility in Tasmania. There were 19 people between 50 and 65 years old who have a residential-classification scale score of between 5 and 8, and 105 people between 50 and 65 years old who have a residential-classification scale score of between 4 and 1 - that being for higher needs. We have split it up that way because nationally that is how they are looking at the information around younger people.

At the moment, there are three younger people with a disability living in hospitals in Tasmania awaiting appropriate accommodation placement. I suppose that is what we are looking at in terms of appropriate accommodation options for people as they move out of the hospital system.

In December 2003 the department held a forum. You may have received a copy of the report 'Younger People in Nursing Homes' and 'Support and Service Models for Tasmanians with High Support Needs.' And we ran a cross-sector forum with representatives from the disability sector as well as from the aged care sector. That looked at the broad service models that are available across Australia. I suppose the main outcome of that was people identifying that individualised support was the most appropriate, basing it on the individual's needs as opposed to a particular bricks-and-mortar-type model.

Ms CURTIS - The reason we ran the forum was that nationally there has been so much discussion about young people and nursing homes. There have been a lot of efforts made in Tasmania but they are all ad hoc. We saw the forum as an opportunity to get all the key stakeholders together to talk about it from a Tasmanian perspective rather than having national people say, 'Well, we can set up a 20-bed home for this group of people' or whatever. We needed to work out what we needed in Tasmania. As Ingrid said, we had some younger people who were living in nursing homes; their family members were represented, we had service providers, and aged care facility providers came. As it turned out, we need to look at them all on an individual basis rather than looking at those group. The report goes into that.

Ms GANLEY - In terms of the current process, within disability Services - in terms of accessing disability services - people may receive the report of the service coordinator. So you would make a referral to Disability Services and a service coordinator would be appointed. They assist people in the coordination of appropriate support services to meet the needs of individuals. That ranges across the services available within Disability Services but also helps individuals to tap into what we would see as generic services-ongoing rehabilitation services; helping them, if they need to move into their own accommodation; or working with Housing Tasmania to secure accommodation. That is across the board for all people with disabilities. If someone has a complex need due to their high support needs, of course it can be more difficult because the client's needs are greater and the cost of supporting can also be greater. They then work, usually with the State office, on how we can actually provide a service to meet the needs of this individual.

Disability Services either directly manages or funds the non-government sector to provide supported accommodation, community support, community access, respite, advocacy and information and referral services.

One of the programs that we fund that has an individualised focus is the individual support program. It currently provides hours of support to individuals for in-home support and personal support. This program is a bit limited in its capacity to provide sufficient hours of support to meet the needs of complex-care individuals. The guidelines of the program specify up to 34 hours a week. In individual cases it can exceed that, though the average package is around the 20-hour mark at the moment. As you might be aware, that just is not enough hours for someone who has complex care needs or higher support needs, so a more encompassing package needs to be developed for those individuals. However, there is the capacity for individual support to provide some of that community access for people if they require it, so in Disability Services we look at tapping into a range of programs to try to meet people's needs, not necessarily always being the one program.

Mr WHITELEY - As far as the 20 hours go, what would your research be saying? The 20 hours need to become what?

Ms CURTIS - By way of example, 34 hours a week works out to be about \$55 000 a year and some of the high support we are looking at is in excess of \$200 000.

Mr WILKINSON - Each?

Ms CURTIS - Yes, each and so you are looking at four times -

CHAIR - Speaking of finance again, just carrying on from what Brett said, and the idea of clients - if that is the correct terminology -

Ms CURTIS - Yes.

CHAIR - pooling their resources; we saw some evidence in Western Australia of situations where residents could pool the services so that they can have a more independent living situation.

Ms GANLEY - Just in the recent 2004-05 budget initiatives, some funding came through for acquired brain injury units to be established and they would be a similar type of model where individuals may be in their own units though they will probably be co-located so they can share that support. People need access to 24-hour support but not necessarily intensively all the time. There are probably key times during the day when they need extra staff.

Ms HAY - Do you think that is a model that works, where they are co-located but have their own private rooms in the same vicinity, a good vicinity for that care? That would work?

Ms GANLEY - Yes, it seems to be and it is a model that some of the sector have put forward to us as working for particular client groups.

Ms CURTIS - Certainly there is a group in Victoria, I think, who have just recently done a similar thing.

Mr WILKINSON - We were there. It was terrific and that is why they are pooling.

Mr MORRIS - What is the quantum of that budget allocation and what are the limits to it?

Ms GANLEY - I would have to get back to you on that. I do not know the final figure.

Ms RITCHIE - Can I just ask some information about the forum that you spoke about. Did you say you had a number of forums and how many people attended?

Ms CURTIS - We actually ran one. It was a statewide forum but it was run at the Woolstore down here.

Ms RITCHIE - I would be interested in the number of participants and where people came from and that sort of information.

CHAIR - Now that we have interrupted your flow, you did say that the clients 'may' receive the services of a service coordinator?

Ms CURTIS - Yes.

CHAIR - Why 'may' rather than 'will' or 'do'?

Ms CURTIS - It is a choice thing, too. Some clients might elect not to have a service coordinator. They might find they have family or whatever that wants to -

CHAIR - Okay. So there are not limitations there in terms of the case load of the workers; anyone who needed one could get one?

Ms CURTIS - Yes.

Ms RITCHIE - Just following on from that, one of the problems that have been raised - and I think we were made aware of that when we were interstate - was sometimes the difficulties with shuffles in employment, such as coordinators coming and going. What sorts of mechanisms are in place to ensure service continuity when staff come and go from Disability Services so that you do not fall through the cracks when your coordinator leaves?

Ms CURTIS - The service coordination teams are made up of a team leader and then the service coordinators in each team. In the south there are three or four different teams, so if a service coordinator leaves their position or moves to another area then the team leader would ensure that there is the flow-on for the client base. Is that what you mean?

Ms RITCHIE - Yes. It was indicated that there were big problems in some instances where coordinators left. The valuable information that they had built up working with particular clients was then lost and in some cases it sounded a bit worse than that. I am interested to know what type of turnover rate we have for people who are working as coordinators.

Mr WILKINSON - There was a death in Tasmania years ago of a young child because of a coordinator leaving and somebody else taking over. The information that coordinator had was not passed through the proper channels; the fellow got life imprisonment for killing a young child.

Ms RITCHIE - Do you have any idea of the turnover of coordinators at the moment? That may be something you can get back to us about.

Ms CURTIS - That is fine. The other thing too is that while Disability Services has service coordinators, a lot of the non-government organisations, depending on their structure, will have a position appointed to coordinating services for the people who are perhaps living in their group homes, or they might have someone who goes through and it is their role to do the personal planning and that sort of thing for the people that they are supporting.

Ms RITCHIE - Are there any checks and balances in place for the private operators who are funded to carry out work to ensure that they are not allowing people to fall through the cracks as well - the same scenario?

Mr GANLEY - There is an evaluation process that all funded organisations have to undertake. It looks at both the organisational and management structure as well as the outcomes for individuals, so it is looking at whether the needs of the individuals being met, whether they have planning processes in place, and then recommendations are made.

Ms CURTIS - And it is evaluated against the standards.

Ms RITCHIE - Do the clients have a satisfaction survey that they are able to fill in as well?

Ms GANLEY - It varies. Some organisations do that but that is organisational specific.

Ms RITCHIE - Right, so there is no overall check from the department's point of view of how the clients, that we are paying other people to look after, feel?

Mr GANLEY - Through the personal outcomes measure we get an indication of that because you interview clients to find out what they think of the service, but it is like a random sample of clients from organisations. They are interviewed with some standardised questions about their outcomes being met and what they know about the organisation. If they cannot communicate for themselves, you speak to the person who knows them best, which may be someone who works with them or maybe a family member or a friend.

Ms RITCHIE - Is that done on a percentage?

CHAIR - I am just wondering now whether it might be worthwhile asking if we could get a proper briefing note on quality assurance, quality control across -

Ms RITCHIE - Yes. I am involved with Oakdale Services Tasmania and am on the board there; we undertake those every year and that is a process and that works very well. I am just trying to get more information as to what sorts of models are happening elsewhere.

CHAIR - If you could, that would be great. Do you want to keep going with your presentation?

Ms GANLEY - Through the 2004-05 budget initiatives, some funding has been identified - and I will get the figures for you - for acquired disability packages for some clients to actually leave hospital. They are individualised funding packages that will go with the individuals to set up services for them in the community. As well, we are looking at developing assessment processes in terms of identifying the need of individuals.

Disability Services also received \$1.5 million through the 2004-05 Budget initiatives for what we are terming 'unfunded' or 'partially funded' clients. These are clients who are currently being supported through Disability Services. If we were not providing that support they may be at risk of entering into a nursing home. Again, that funding would be targeted as an individual support package or funding arrangement. So when an individual at risk of being accommodated in a nursing home is referred to Disability Services, all attempts are made to meet their support needs from within the current system. However, sometimes at present the requirements may fall outside the available resources. That is why in some instances younger people may end up in an aged care facility.

CHAIR - So what you are saying is that there sometimes is not enough money to provide an individual service package for a young person and therefore they have to go into a nursing home.

Ms CURTIS - Not necessarily. There are other mechanisms in place now with the community support subdivision. They have the Board of Exceptional Needs, which looks at clients with complex needs. They are looking for alternatives, I guess at an agency level. So that is when we bring in Housing, some of the nursing aspects and that sort of stuff. It is a bigger picture, beyond just Disability Services.

Ms GANLEY - That leads us on to current research. You may be aware that the National Disability Administrators have commissioned a research project on the support needs and service models for younger people with high clinical care needs, and Disability Services is represented on that steering committee. They are tendering out a project to look at models and appropriate supports nationally for people with high clinical care needs. Also, under the Commonwealth and State and Territory Disability Bilateral Agreement there is a commitment in Tasmania for the Australian and Tasmanian governments to work together to develop strategies for providing the most appropriate form of accommodation to meet the individual needs of a person with a disability. In particular, this is looking at the appropriateness of accommodation for younger people currently living in aged care facilities and older people currently supported in state-funded group homes. Both Annie and myself are on that working party, which has been meeting since October 2003, looking at the development of an agreed assessment process to determine the most suitable accommodation and looking at workable strategies for moving younger people with disabilities into more appropriate accommodation.

Mr WILKINSON - That has been going on now for a number of years, hasn't it? I know the Brain Injury Association and a few other organisation have said now for many years that there is a real problem in relation to people with acquired brain injury who are not on MAIB payments going into these homes. There must have been a lot of studies done in relation to it, I would have thought. Or am I wrong?

Ms CURTIS - I guess that is going back to before the forum. There have been a lot of ad hoc bits and pieces that have been done. At the same time, there has been a bit done nationally. In Queensland, I think, they did a fair amount of research into acquired brain injury and accommodation. However, again it is whether we can actually apply this sort of research to Tasmania. The numbers we are looking at are a lot smaller and we need to focus so much more on the individual rather than on having a specific model.

Mr WILKINSON - So the study you are doing now is taking into account everything else that has gone on up to this stage, but coming up with something peculiar to Tasmania?

Ms CURTIS - Yes, that's what we're aiming for. The next task that the working party is going to undertake in this financial year is a survey of younger people - all the people under 50, which is just a nominal cut-off age, who are currently living in nursing homes. The survey will involve them and their families and the aged care facility. We can talk about numbers and that sort of thing but until we actually talk to the individuals and the people who know them best we will not get a real picture of what is appropriate and what is not appropriate.

Mr MORRIS - So that is the 26 you talked about and the three in the hospital?

Ms CURTIS - Twenty-three.

Mr MORRIS - Twenty-three and the three in the hospitals, so 26 that you are going to actually survey?

Ms GANLEY - Yes.

Mr MORRIS - And for those who are over 50?

Ms CURTIS - Initially we are going to wait for the outcomes of the first group, and then the working party will certainly have to look at that next group. Nationally, there has been a huge amount of debate about cut-off ages and that sort of thing.

Mr MORRIS - Yes.

Ms GANLEY - Again, it is a matter of talking to the individuals about the appropriateness of their accommodation, bearing in mind that some people are accommodated in aged care facilities in rural areas, which means that they are closer to their family. We had a couple of people at the forums who wanted more access to the community but were quite happy with their actual accommodation. They just wanted to be able to access the community more; they were based in a rural community and were near their family. We wanted to get the opinions of the younger people as well, as to what would work best.

Mr WHITELEY - I may have missed that, but at the start did you talk about the percentage of those in built-up suburban city areas compared to rural and regional areas?

Ms GANLEY - No. We could look at that figure.

Mr WHITELEY - That would be very useful. Not to diminish their value but just to see -

Ms CURTIS - Again, I guess that will be picked up through doing the survey, as well as the physical location of the aged care facilities.

Mr WHITELEY - It would be terrific to see dots on the map as to where the clusters are, because at the end of the day you need to be pragmatic.

CHAIR - The committee could not assume that just because a young person is in a nursing home that they do not want to be there.

Ms CURTIS - That's right. Again, the issue of where their bed is - they might be quite happy with that. However, it is access going out into the community, to therapy services and to equipment that might be the issues for them. You can appreciate that they would not necessarily want to be sitting around singing or whatever it might be. There are a few people who have contacted our office and said, 'I don't mind where I am living and I access the community one day a week'. I would really benefit the client if they could access the community, during the day, five days a week. For that individual there have been really positive outcomes from not being stuck in the nursing home all day.

Ms GANLEY - That's where this working party with the Commonwealth is quite important, because then we are entering into those dual funding arrangements in terms of how do people who are in an aged-care, Commonwealth-funded service access state funding for their day activity. That is sometimes a very big barrier for people.

CHAIR - Can you give us a hypothetical of how it gets complicated? Because I find really confusing this business of State and Federal and who pays what and when. If I had an accident tomorrow so that I required residential care and my needs were so high and I lived in the local area and was quite happy to go into the local aged care facility, where would it get complicated in terms of who pays for what?

Ms CURTIS - The Commonwealth would fund your bed. So you would get x amount of dollars.

CHAIR - And that is regardless of age?

Ms CURTIS - You are assessed as being an RCS level 1 through to 8, and the dollars would depend on the level you are assessed at. The Commonwealth would contribute that amount of dollars.

CHAIR - And I am on the disability pension, I presume?

Ms CURTIS - Yes. I am not sure how the aged care facilities work, but they tend to take a percentage of the pension - a fairly large percentage.

Mr MORRIS - Eighty-odd per cent.

Ms CURTIS - The lines become hazy for things like community access. If you wanted to go out into the community and have individualised day activities and that sort of thing, the Commonwealth would see funding that as the State's responsibility.

CHAIR - What about rehab, if I need that?

Ms CURTIS - In essence, the level that you're funded at for the aged care facility should cover therapy and all that sort of jazz, but because your therapy needs would probably be a lot great than someone who was frail aged -

Ms GANLEY - You would want to access the State-funded therapy services and then there would be a complication of how you actually get there. The residential service might have its own vehicle but it has been transporting the residents of the aged care facility to day activity programs and it does not have the capacity to help you get to the therapy service, or the therapy service cannot come in to the residential aged care facility.

CHAIR - Or it comes and that person does not have the kind of skills or equipment that I need if I have a particular long-term injury that needs treating.

Mr WILKINSON - My wife is a physio and she does a bit of work with this. They have a practice down here but the Federal Government is paying for them to go up to Swansea and Bicheno to do this type of work. My understanding was that that is a State issue and not a Federal issue.

Ms CURTIS - To an extent the aged care facility would fund the therapy service but it would depend on the level of support that was being provided.

CHAIR - Who would provide specialised equipment, like lifting equipment? Getting back to me and my problems.

Ms CURTIS - Again, the aged care facility should fund the equipment and that sort of thing from the level of support that you have been assessed at. However, in reality that does not occur. Disability Services - through our individual support program - has funded some equipment like wheel chairs and that sort of thing. Once we start talking about motorised wheelchairs we are talking about anything up to \$20 000. The State has the Community Equipment Scheme but that does not cover people in aged care facilities. So Disability Services' individualised support program has funded some equipment. We are getting more requests.

Mr WILKINSON - Is there in easier way to fund it? It does seem confusing to me. If you were starting afresh, would you fund the system in the way it is funded now or would you fund it in a more transparent way, so that people could actually see where the funding was coming from?

Ms CURTIS - I'm not sure. I am really interested in the outcomes of the survey in terms of whether we can delineate between what is the Commonwealth's responsibility and what should be the State's. Then we can start playing around with money and that sort of thing.

Ms GANLEY - I know the consumer base would prefer a more flexible system. By having aged care responsible for this and Disability or State responsible for this, you might be living in an aged care facility and you want to access some State-funded equipment but you cannot just because of where you live. If you lived somewhere else you would be entitled to that. We get a lot of requests and we would like it to be more flexible. That does not really answer your question but I think it is about how we can make the system flexible and also equitable so that people are not being doubly funded, getting their equipment from the community, getting a bit of equipment so that someone else misses out.

Mr MORRIS - From the State's point of view, once a person has had an injury, if they are a young person they effectively are the State's responsibility if they have no other way of covering it. If however they then find themselves being accepted for an aged care facility and the Commonwealth then picks up the funding for their bed - and they are getting the pension, presumably - why is it then dependent on where they live, if they are in a nursing home? Why does the State have difficulty in funding that extra support, given that if the person was not in there and was not getting Commonwealth support the State would have total responsibility for them?

Ms CURTIS - The younger people who are in nursing homes in Tasmania at the moment seem to have been there for quite a while. To me it would not seem like a difficult thing for the State to say, 'The Commonwealth has funded this bit and we will pick these people up as a priority'. To be honest, I do not know why that barrier seems to be there.

Mr MORRIS - Do we know anyone who might know why? It does seem to be quite crucial. I know that the dual funding it a problem and it gets raised so often as a constraint to moving forward in the system. There must be someone, either in the Commonwealth

system or in the State system, who knows why these barriers have not been worked through.

Ms RITCHIE - I think that question is a policy one for the ministers involved. To follow up on what Tim is saying, I think you said that the 23 we are dealing with at the moment have been there for a while. That would be because - and you can correct me if I am wrong - the ACAT assessments have changed significantly and it is much more difficult now for a young person to get in at all?

Ms CURTIS - It is a combination of things. The ACAT assessors do not look at nursing homes as an option for young people unless they have been through everything else. With community support - and I was talking earlier about the Board of Exceptional Needs and looking at complex clients - again, it is looking at appropriateness. There are a few examples currently of individuals who are in hospital or have recently been in hospital. Every stone has been turned over to try to work out how that person could return to live in the community rather than going into an aged care facility. I guess because there has been so much attention to the issue it is not really considered as an option any more.

Ms RITCHIE - Now, for a young person to get into a nursing home it would be because they require that environment?

Ms CURTIS - It would be combination of the level of their support needs and nursing needs and where they live - in terms of other facilities available - and their choice of remaining in a small community or whatever it might be. Again, it comes back to an individual basis.

CHAIR - Do you have any idea when the survey results would be available?

Ms GANLEY - It was aimed to do it this calendar year so we would have it by next February.

Ms CURTIS - The working party is meeting, I think, over the next month. So that will give us the next step.

Ms GANLEY - I think I am almost at the end of the notes that I brought. I suppose the main body of work for us is working with the Commonwealth on options for younger people. We have certainly raised that issue of flexibility of funding. I know it does not relate to younger people but we have a similar issue with older people living in State-funded accommodation services and who are not eligible to access HACC funding or other aged care funding. Maybe if they could get a community aged care package into their funded group home they might be able to have some supports that they currently do not get. Again, that does not happen.

Mr MORRIS - That is because they have been in a State-funded system prior to being eligible on an aged basis?

Ms GANLEY - Yes.

Ms CURTIS - And then that also opens up the debate of ageing versus disability.

Ms GANLEY - Yes, we are certainly discussing that with the Commonwealth members on the working party.

Ms CURTIS - The Commonwealth are very enthusiastic about the issue at the moment.

Mr MORRIS - Good. So it sounds like progress is being made at the moment. There is a good deal of attention being focused in the area and that has led, firstly, to pretty much a cessation of young people going into nursing homes. As we heard in Western Australia, a lot of young people who were in nursing homes are coming out of nursing homes. So it sounds like there are some positive moves but there are still some crucial areas in the funding that need to be sorted out. From that point of view, it is very encouraging so far.

Mr WILKINSON - The study you are doing, when do you think you will finish that?

Ms CURTIS - Through the survey?

Mr WILKINSON - Yes.

Ms CURTIS - The working party has been established under the Commonwealth, State and Territory Disability Agreement. The life of that is to 2007. One would hope that by then all the people who are deemed inappropriately placed would have had funds identified to give them the opportunity to go to a more appropriate service model.

Mr WILKINSON - What recommendations would you give a committee such as ours?

CHAIR - That's a bit rough; you are talking to senior public servants.

Laughter.

Mr WILKINSON - It is a fair question. If you were starting afresh you would ask what is needed. If you had a utopian position, what would it be?

Ms GANLEY - I think it is focusing on the individual need. As Annie was saying, in Tasmania we are not looking at high numbers, so you cannot say we want to create a type of model that will accommodate 20 people' when there might not be 20 people. It is more about what individuals need. Sometimes that can cost - some packages are more expensive than others. It is about the capacity for the State system - or for any system - to cope with the individual needs.

Mr WILKINSON - So it is an economy-of-scale argument really, like hospitals. We cannot have four hospitals in Tasmania or even three hospitals because we do not have the economies of scale for that. Is it the same with care for people with disabilities?

Ms CURTIS - Quite possibly. For example, in Victoria the MS Society have a 15-bed wing of a nursing home that is focused on younger people with MS. They access all the therapy services and they have community access. Apparently it is a brilliant facility for people with MS. In Tasmania we work quite closely with the MS Society and they have identified younger people who are in nursing homes. Some of them are appropriate and

some of them are not according to the MS Society, but we would never need to have a 15-bed place specifically for people with MS.

Ms RITCHIE - You did say that we are talking about small numbers here: 23 plus 3 in the hospital situation. Do you think that there are significant numbers of other people who are not in the system because they are cared for by family who do not want them in the system because they do not think the system is good enough - they are not confident - and they are struggling? How many of them would there be? If you added those people into the scenario of people who may at some point want to utilise services if they think it is appropriate or can no longer carry on, then how many people are we talking about?

Ms CURTIS - That's a hard one to answer; in terms of all support and disability services, the issue of ageing carers is one unmet need.

Ms RITCHIE - Particularly for young people with disabilities.

Ms CURTIS - Yes.

Mr WHITELEY - Are you saying - this is not a trick question - that we do not have a handle on that data?

Ms CURTIS - It is a bit hard to tell. We have a lot of data about what services are provided and we have data around waiting lists, but we do not necessarily have data around people who have not put their hand up and said 'I am going to need support in five years' time' or 'I am going to need support in 12 months' time.'

Ms RITCHIE - But there would be a lot of people out there who are getting perhaps small bits of support. They are probably not happy with what they are getting - whether it is a day service one day a week for their child or relative or whatever it is - and they are still not getting enough but they are not out there ringing the bells and imposing themselves because they are carrying it the best they can. I would have thought that we would have a pretty good idea. We would be able to look at it and say 'Mrs Bloggs has a son that she is caring for but we can see that in 10 years she is not going to be able to keep doing it all'.

Ms CURTIS - Through service coordination they keep a list in each region of people who have been identified as going to be needing accommodation or support between now and x years' time. So there is that information.

Mr WHITELEY - Would they have that information broken down into categories of condition: MS, Huntington's, ABI?

Ms CURTIS - We can certainly ask the question.

Mr WHITELEY - It would be great to know if they have that: the data that Allison has referred to - quite correctly - and, secondly, whether they have it broken down into categories of condition. That would be very helpful.

CHAIR - We have asked for quite a bit of information. Do you have it all down?

Ms GANLEY - Yes. We have: ABI figures around the 2004-05 Budget initiative, the turnover rate in service coordination, briefing on quality assurance evaluation of services, percentage of younger people in rural areas versus city -

CHAIR - Actually they could be raw figures because they are so small. Percentages wouldn't mean a lot.

Ms GANLEY - Yes. There was that general question of the barriers between State and Commonwealth funding, and data around accommodation needs based on condition.

Mr WHITELEY - Kathryn's just added a point. I was more interested just to get an idea as far as people's condition goes. But Kathryn's right, it would be also helpful if those service coordinators - who have a sort of forward mapping system? - have data that we would be able to have access to. That would be helpful.

Ms GANLEY - Yes.

CHAIR - Some future needs stuff you couldn't map though, surely?

Mr WHITELEY - I was more interested in where they are sitting at the moment.

Mr WILKINSON - But some of it you can. There was a meeting up in Launceston and Pammy Walters I think gave some evidence. She is mixed up with a disability - I have forgotten which one it is - and they are looking at families because it is genetic.

Ms GANLEY - Huntington's.

Mr WILKINSON - Was it Huntington's? I am not too sure what it was. It is a bit off beam, but this goes into a whole new area with genetic modelling, examining your genome to ask 'Are you prone to getting rheumatoid arthritis?' or 'Are you prone to getting Huntington's?' and that type of thing. That is the only way you are ever going to know exactly.

Ms GANLEY - Yes, true.

CHAIR - It may well be we would like to have you back at a future time. I hope that will be okay.

Ms CURTIS - Yes, that's fine.

CHAIR - Perhaps after you have had your next working group meeting. It would be interesting to get an update on the progress with that. Thank you very much for your time and your contributions.

Ms GANLEY - We have copies of the overheads that we used at the community forum, which have some more information on them. Some of the statistical data is from last year so it is a year out of date, but it gives a general view of the split across accommodation and community support and things like that.

Ms CURTIS - And keep in mind that people were talking to these overheads so you will get ones that just have a heading.

CHAIR - Thank you very much.

THE WITNESSES WITHDREW