

**COMMUNITY DEVELOPMENT AND JUSTICE
STANDING COMMITTEE**

**INQUIRY INTO ACCOMMODATION AND INTENSIVE FAMILY
SUPPORT FUNDING FOR PEOPLE WITH DISABILITIES**

**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
WEDNESDAY, 12 MARCH 2014**

SESSION ONE

Members

**Ms M.M. Quirk (Chair)
Mr I.M. Britza (Deputy Chair)
Mr C.D. Hatton
Mr M.P. Murray
Dr A.D. Buti**

Hearing commenced at 10.09 am**Ms SUSAN DOREEN PENBERTHY SHAPLAND****General Manager, Member Services, Multiple Sclerosis Society of Western Australia, examined:****Ms FRANCES BUCHANAN****Operations Manager, National Disability Services WA, examined:****Mr TERENCE WILLIAM SIMPSON****State Manager, National Disability Services WA, examined:****Mr DAVID GRANVILLE****Director, Service Development and Strategic Relations, The Centre for Cerebral Palsy, examined:****Ms NORELLE MORRIS****Chief Executive Officer, Valued Independent People, examined:**

The CHAIR: Good morning everyone. On behalf of the Community Development and Justice Standing Committee, I would like to thank you for your interest and appearance before us today. The purpose of this hearing is to assist the committee in gathering evidence for its inquiry into accommodation and intensive family support funding for people with disabilities. Have you have been provided with a copy of the committee's specific terms of reference?

The Witnesses: Yes.

The CHAIR: I am Margaret Quirk, the Chair—it is nice to see you again Terry; it has been a while. The Deputy Chair, Ian Britza, is absent today. On my right is Dr Tony Buti, the member for Armadale. On my immediate left is Mr Chris Hatton, the member for Balcatta and on his left is Mr Mick Murray, the member for Collie–Preston.

We are a committee of the Legislative Assembly and so this hearing is a formal procedure of the Parliament and therefore commands the same respect given to proceedings in the house itself. Even though the committee is not asking witnesses to provide evidence on oath or affirmation it is important that you understand that any deliberate misleading of the committee may be regarded as contempt of Parliament. This is a public hearing and Hansard will be making a transcript of the proceedings for the public record. If you refer to any document during your evidence, it would assist Hansard if you could provide the full title for the record. Before we proceed to questions that we have for you today, I need to ask you a series of questions. Have you completed the "Details of Witness" form?

The Witnesses: Yes.

The CHAIR: Do you understand the notes at the bottom of the form about giving evidence to a parliamentary committee?

The Witnesses: Yes.

The CHAIR: Did you receive and read the information for witness briefing sheet provided with the "Details of Witness" form today?

The Witnesses: Yes.

The CHAIR: Do you have any questions in relation to being a witness at today's hearing?

The Witnesses: No.

The CHAIR: You have made a submission to the inquiry?

Mr Simpson: Yes, we have.

The CHAIR: Is there anything you want to add to the submission or change at this stage?

Mr Simpson: Nothing that we want to add or change. We had come prepared to speak further to that.

The CHAIR: Yes, that is fine. We have a series of questions to ask you today. Before we do that, is there any additional information you want to provide to us at this stage?

Mr Simpson: We are able to speak in elaboration to that submission and by way of background to the submission. Thanks for the opportunity to appear here today. NDS, as indicated in the submission, is the peak organisation for the not-for-profit disability service organisations, and the submission was compiled by a number of our service provider representatives, a number of whom are here. I am happy to give a brief overview in terms of our response to each of the three questions, and then others, who are more expert than I, are happy to add to that. Are you happy for us to proceed on that basis?

The CHAIR: Yes, thanks.

Mr Simpson: With regard to question 1, the key problem with the CAP process is that there are not enough funds to meet the needs, and that creates real issues for that process from the start. From our point of view, there is also a lack of information regarding the prioritisation of funding such as how those decisions are made, and around its capacity just to respond to critical and urgent need. Applicants virtually see themselves as having to prove that their situation is worse than others. This can be a hugely destructive process to people and to families to portray their situation as a failure to cope and often for family members to have to talk about the impact on them of supporting the person with disabilities. The process is hugely destructive on families. Two of our members, Rel Morris and David Granville, are prepared to provide some case examples that are more illustrative of those issues.

Mr Granville: I have been in a number of roles over the years, and I have been intimately involved. I sat on the CAP panel rounds and actually chaired some of them. It is an illness and deficit type of model where you demonstrate just how bad your life is. The issue is that with the last CAP round 350-odd people applied. There were 15 from the centre and Norelle probably had an equal number from her organisation of the individuals we were supporting who were funded.

The CHAIR: How did you get those figures? One of the things we are getting in evidence is that that information is not readily available anymore.

Mr Granville: Confidential reports are given to each of the organisations who put up funding applications. It is a confidential document that is sent to us and Rel, but 400 to 450—you can probably get information in the past where the commission has similar numbers. If you look at the accommodation support and leave respite to the side, say there are 430 and 30-odd of those get funded in one round, so there are 400 people who are not funded. That is also the tip of the iceberg. I have a step-daughter with an intellectual disability. My wife and I do not even bother applying for a CAP funding package or accommodation because we know we have between Buckley's and none—that is a technical term—of getting support, and there are a number of other families like that. The other side of the coin is do we want a process where it is devolved and we do not capture that need? I suppose we are weaving into question 2 a little bit. Norelle, did you have anything else to add?

Ms Morris: I have a couple of examples that I will bring to the table. Two of them are examples of two different scenarios that are very likely to happen for families and individual who want to apply for accommodation funding. One of the families includes an older set of parents in their early 70s.

They have been working with the Local Area Coordination program through the Disability Services Commission for approximately 10 to 12 years. They both have ailing health and physical conditions. Their daughter has cerebral palsy and extreme and complex support needs, physical and otherwise. They were finding that whilst they were happy for her to be at home and they wanted her to remain part of the family unit, they were provided with some intensive family support funding over the years to help them with in-home support, particularly around the hoisting and transferring and things like that. They could cope with the rest of the care, but there were certain things that they were obviously not able to do. Obviously the promotion of individualised service models is around planning. This family had been planning for 10 years saying their health had been getting worse, their physical capacity to care for their daughter had been decreasing year after year, and that they would be going into retirement and selling their house. That has now happened. I have been involved in their particular process for over two years. They have not been successful in the CAP round. They have reams of evidence and paper around the planning, what the timeframes are from the beginning to the end, and they are still not up. Now they are moving in two weeks and their daughter has nowhere to go at this stage.

Mr M.P. MURRAY: Why has she not been accepted?

Mr Granville: Of the 430 individuals who apply for CAP, a panel of independent assessors—some are parents as well as individuals with disabilities—make an assessment judged on the family's situation. They look at a number of risk factors—homeless, harm to themselves, their medical needs and their behaviour. They look at some major issues and make an assessment or a judgment. It is a pretty horrible and soul-destroying process.

[10.20 am]

The roughly 30 who get funded is based on the available dollars. If they have X number of dollars to allocate, they stop allocating when they run out. There are still a large number of people below that point who have a high need and a high rating but the dollars do not go that far. This family are probably number—I hate using this crass term—50 or 60, and in the next round there will be a new set of individuals and families who go into the process.

Ms Morris: There is no prioritisation on the CAP list. In the past it used to be where a person would move up a list depending on their level of need, and obviously a lot of that would increase with time. That is not the case anymore. New applications come in and they are all reassessed all over again.

The CHAIR: Dr Chalmers told us that the problem with this list and having a person moving up on the list is that someone might come in at the end of the list and have chronic needs —

Ms Morris: Critical and urgent needs. “Critical and urgent need” is the key phrase around the whole CAP process, which is to try to meet that critical and urgent need. The issue is what do you do when there are 400 people who are in urgent and critical need? We all acknowledge the bucket of funding that is finite.

The second situation I will tell you about is of another family. The lady with the disability who is with my service has five siblings, all of whom have three different fathers. The mother is single and has said for many years that she is in crisis. We have had absolute concerns about this young lady's wellbeing in the home. Her personal care needs are not being met. It has got to the point where we have lodged the appropriate documentation with disability services. We have a SAT application ready and waiting to put in.

Mr Granville: Letters of support from my organisation as well.

Ms Morris: Letters of support as well as people with disabilities are also involved in this situation and today we are providing 24/7 respite to this young lady for a four-week period to improve her mental and physical health so that once that SAT process has begun, she can be in a better state of mind and health to be able to make —

Dr A.D. BUTI: Is it a guardianship application?

Ms Morris: Yes. As I was saying, to make an informed decision about the choices. She wants to remain in the family home but there are so many issues within that and her needs being met around, well, everybody's willing to be able to do something. Again, this is a CAP application that once again has been rejected in that last round. They are two very different examples of people playing the system, and I do not mean that with any disrespect. They are simply going through the motions, doing the planning and being aware so that yes, we know in 10 years you will need X amount of money for an accommodation package for our daughter. Then there is the complete opposite where it is an urgent and critical need about the duty of care and wellbeing to an individual that we predominantly provide day supports and very small respite—overnights here and there—to the people who have been with our organisation for over 20 years. These are just two very clear examples where that process has failed both of those families.

Mr Granville: I do not think anyone here would argue that planning needs to be a key element in anything for supportive families and individuals, but you do a lot of planning, and we know there are some life stages—early intervention years, school—so we know roughly when the needs change. A lot of planning is done but then, bang, they go through a process that does not really take that into account unless you can demonise yourself.

Dr A.D. BUTI: David, you talked about being on the CAP tribunal at one stage. Did you read every single application?

Mr Granville: Yes.

Dr A.D. BUTI: When you were on the panel, how many?

Mr Granville: On one panel I read 350 applications. I was effectively working full-time plus going home and reading these applications. Yes, we read every application.

Dr A.D. BUTI: Is there is a set criteria that you apply?

Mr Granville: The CAP panel members do not know what rating goes with each score that you will look at. If Tony's medical needs are non-existent, that is a high rating—tick—and you will do a rating and you will go through each risk factor, I suppose.

Ms Morris: So it is an electronic tool.

Mr Granville: So whether you are at risk of becoming homeless or you are homeless. It is a tool.

Dr A.D. BUTI: So it is completely a paperwork and assessment?

Mr Granville: Yes.

Mr Simpson: The lack of adequate funding is the key to all this. I have heard many stories from families who talk about the fact that they have to go in there and totally exaggerate the amount of dysfunction in their family and their lives to give themselves a chance. People talk about threatening suicide as a way of elevating their situation up the priority list.

The CHAIR: The problem is that if you do not get it, you have bared your soul in these documents, you have realised your situation is really bad, and then you are expected to carry on.

Ms Morris: Exactly, and you require more support.

Mr Simpson: It is not just your soul. You have bared your whole family to this process and then the family has to put itself together and move on.

The CHAIR: Dr Chalmers came along with a graph to say that this is increased funding, but there is an increased demand, as I understand it, and, obviously, when you have ageing people who were previously cared for by their families, the families are ageing, so there is a cohort of people who were outside the system and who will now be going to be in it.

Mr Simpson: And getting increasingly desperate.

Mr Granville: You could argue, being the cynical person that I am, that if you look at the budget papers for 2013–14 and the previous years, the growth if you look three years back was good. The out years from this financial year onwards is really just indexation. Minus the indexation and it is really just one, may be one and a half per cent growth. That is hardly growth.

Dr A.D. BUTI: We were told by Dr Chalmers that there had been unprecedented growth—14 per cent growth—in funding. But there are increased numbers of people probably applying and an increase in the cost of living.

Ms Morris: And as for the ones who have been on the process for a number of years, if you have been in that process for 10 years and have not been funded, chances are your need is much greater today than what it would have been at any other point in that 10-year period had you been funded.

Mr Granville: A lot of that 14 per cent growth you could argue is catch-up in that it is addressing some historical underfunding of individuals and organisations. It was not necessarily funding for new individuals.

Mr Simpson: I think that would be fair. As per the Productivity Commission report across Australia, this is an issue and, hence, the decision to go ahead with the National Disability Insurance Scheme that the funding really is inadequate. Unfortunately, and I guess moving along to the level of unmet need, that is not particularly clear. There is not good, publicly available data. Certainly from the data that is available, the amount of unmet need is quite substantial. One issue of concern to us in terms of the current budget papers is the absence of provision for growth funding in the forward estimates, which we would very strongly hope gets rectified in the coming budget. It is important to also state that additional funding should not just be allocated to the trial sites or the NDIS. Although the NDIS is coming, for families who are in a critical situation, 2018 or 2019 is still a helluva long time away. It is critical there be continued provision for growth funding across the state to address as much as possible of the critical need in the intervening years until the NDIS is rolled out.

The CHAIR: We were wondering whether some of the money that would have probably gone in has just been hived off to do the preparatory work for NDIS and run the trials and what have you. Do you think that is what has happened?

Mr Simpson: I have not seen evidence to support that but I think it is imperative that that not happen. We have another budget coming up and that will be the test, the extent to which there is growth funding that is quite separate and distinct from the funding under the commonwealth state agreement for the trial sites, and to continue to cater with just the enormous and growing unmet need across the entire state, otherwise we will have enormous inequity between the trial sites and the rest of the population.

The CHAIR: Can you tell us a bit about Aboriginals, because they are not engaged with the system, by and large, and the level of unmet need there and what needs to be done to better accommodate their needs?

[10.30 am]

Ms Buchanan: I can talk a little around the lack of knowledge about known need with Aboriginal populations, particularly in rural and remote areas. We know historically that Indigenous people often do not engage with services at any level. We know, for example, that Australian Bureau of Statistics' figures do not necessarily capture whole populations. Indigenous people are often loath to engage with government. So although we know a little about the need in remote areas, as well as metro areas, the extent of known need has not been captured at all. In addition to that, where we do know the need, we also know that historically there has been a limited sector response to Indigenous people with disability. There is also a limited engagement of Aboriginal people as employees to provide services. National Disability Services did a research paper around that about

two years ago, and that identified some of the key issues. So there is a lack of engagement on both sides of the process, plus the unknown need.

Mr Simpson: There are issues for government in that, but there are also issues for the sector in that, as a whole, our sector has not engaged well with Aboriginal people. There is very low employment of Aboriginal staff in the sector. That is something that we are hoping to do something about, and we are hoping to get some funding from government to help the sector make those changes.

The CHAIR: There was a campaign in 2006, in which I was involved, to publicise what DSC services were available. But I left before we got the evaluation of the outcomes of that. But that is obviously a problem.

Mr Simpson: What we are hoping to do on a small scale, with some funding that we have, is work with a number of organisations to develop stronger connections between those organisations and the Aboriginal community, and get some fairly substantial recruitment of Aboriginal staff as trainees into the sector. Certainly from my experience in other sectors, if Aboriginal people see organisations that are basically all white faces and do not understand their cultural issues, they do not want to go there. Most of what we know about the need for disability services is based on people fronting up and asking for services. But Aboriginal people are not fronting up, because the sector is not one that they see as necessarily achieving their needs, so that underplays the need. Another thing I would say is that compared with other sectors I have been involved with, there is an absence of Aboriginal-controlled organisations in the disability sector. I see that as a twofold thing—the current sector gearing up to better serve Aboriginal people, and the need to look at how Aboriginal organisations can take on some responsibilities in that area.

Mr C.D. HATTON: Terry, you would know that this model where Indigenous people are trained up to look after their own people has been around for a long time. Is the need for that becoming more obvious now than it has ever been?

Mr Simpson: Certainly within the sector there is a growing awareness that for us to serve this population better, there needs to be some change. There has been a substantial project run out of NDS in New South Wales with a very high level of funding from the New South Wales government, which has been around supporting the sector to engage with Aboriginal organisations and bring in Aboriginal employees as trainees. That has been hugely successful and certainly we would like to move in that direction. But we need to get the resources, because for each organisation to try to do that individually is a huge task, whereas collectively, if we can provide some support around that, there is a far greater chance of success.

Ms Buchanan: The New South Wales project also uses groups of Aboriginal people who are key within their community to identify what their needs are for their people with disability. So it is a very grassroots approach, which I understand has been quite successful to date.

Mr M.P. MURRAY: This is a difficult question, I suppose, in one sense, but just to help me understand, is there an average age for multiple sclerosis and other disabilities? You said to me that someone's daughter cannot get accommodation. Some of these people live to 70 or 90. For a person with a disability, is there a cap on for how long they live? That sounds like an awful question, but I am trying to understand the longevity of these people.

Ms Shapland: With multiple sclerosis and a lot of other degenerative neurological conditions, although there is generally some ability to, I suppose, identify the potential lifespan, a lot of the time it is very variable, because each attack, particularly with multiple sclerosis, can affect people in different ways. Some people with a more progressive, aggressive form of the disease can be dead within a couple of years. Most people with MS have a lifespan only 10 years less than the average lifespan of the normal population.

Ms Buchanan: For people with disability, it is actually very broad. Some people who are diagnosed when they are born as having a disability may live to adulthood and into old age. People with Down

syndrome, for example, may as part of their condition have a heart that is not that strong, but they may live to an older age. Individuals who are diagnosed at the age of three with muscular dystrophy—usually young men, sadly—usually do not live beyond 30. Then there are people who acquire an injury through a car accident or some other sort of trauma. It is really a case of how long is a piece of string.

Mr Simpson: One thing that is very clear is that in previous generations, generally people with severe disability did not outlive their parents, whereas that has changed dramatically with better care and better medical intervention, so an increasing number of families are facing the dilemma of what will happen to their child when they pass away.

Mr M.P. MURRAY: That is why I wanted to know.

Ms Shapland: This is where the CAP process does not work, because you are trying to fit everybody into the same basket. For people who are born with a disability, generally one would think that if they have the ability to be proactive and plan, they can, as was discussed before, identify some key milestones, particularly that as the parents age, accommodation will be required. But with people who live full and healthy and normal lives and often have professional jobs and are well engaged and have young families, if they are suddenly struck by injury or get a diagnosis of something that is life-limiting and progressive, that is where the system needs to be more responsive, because if people are ranked and queued and other people are jumping on the list, they are never going to get funding, and that was the experience—people were dying before they got funding.

Dr A.D. BUTI: If I can get back to the issue about not enough funding for this sector, in a lot of welfare areas, if people qualify, they get support. At least at Homeswest, they have a priority list. You do not even have a priority list. In your estimation, is it possible for governments to provide enough money so that everyone who qualified—you would need to have a set of criteria—would be able to receive housing within, say, a maximum of six years from when they apply? Do you think it is feasible that governments could provide enough money so that people who qualified and met the set of criteria would be able to get housing within six years?

Mr Simpson: Leaving housing aside —

Dr A.D. BUTI: I am talking about accommodation support.

[10.40 am]

Mr Simpson: Yes. The premise of the National Disability Insurance Scheme is that it is an insurance model where if people qualify, they will get support. There is a lead-in time of about five years or so before that will roll out across Australia. But the intention is that when that scheme is in place—and the trial sites will have to test the assumptions underlying that scheme—people who qualify and meet the standard will get support. I guess that is the light at the end of the tunnel.

Dr A.D. BUTI: It may not be, though. That may change.

Mr Simpson: It may change and we are watching the commission of audit with interest. The other side of that is the national injury insurance scheme proposed by the Productivity Commission. The responsibility for that rests with the states. The first step towards that is to establish the no-fault motor vehicle accident insurance scheme. Western Australia is one of a diminishing number of states that has not taken that step yet. That is really critical because in terms of people who suffer catastrophic injuries through motor vehicle accidents, depending upon whether they are compensable or not, one can receive huge amounts of care and the other nothing. Many of those who receive nothing, though, come into CAP rounds. Some get there; most do not, but those who do get there are therefore reducing the size of the CAP pool that is available for the rest of the population. I guess from our point of view, from many perspectives, it is really critical that Western Australia move ahead quickly down that line.

Dr A.D. BUTI: Do you think there is merit, in saying that—I know that under the National Disability Insurance Scheme, this is what should happen—in having a maximum waiting period, and if you qualify, by a certain period of time you will get that accommodation support?

Ms Morris: I suppose it gives a level of certainty, but whether or not it improves the quality of life of those people who are still having to do that—I mean, it is not going to change anything.

Dr A.D. BUTI: It may improve the fact that you do not have to put out all your laundry in the application process.

Mr Granville: Yes, but the dollars: let us just look again at the figure I plucked out of 400 individuals who missed out. If you look just at accommodation, not even the large respite packages, an average figure, I think, would probably be about \$150 or up to \$200. If we say \$150; that is \$60 million and that is in round 2 of 2013–14 recurrent ongoing, and there will be new individuals. The amount of \$60 million is not a small amount of money.

Dr A.D. BUTI: That is enough for the musical toilets in the new football stadium!

Ms Shapland: Could I also say that the accommodation support —

Dr A.D. BUTI: Can you take that off the record?

Ms Shapland: The accommodation support funding requests are not all about accessing supported accommodation options; they are about accessing care packages for people who live on their own in the community, so they come under the band of accommodation support. These are people who need a package of care to maintain some semblance of normality and have support with activities of daily living. Some of those packages are relatively small but even they do not get funded.

Mr M.P. MURRAY: We were told in here about the process of applying and as you got to the bottom, if you missed out, there were—I think the words were—“many opportunities to get funding from other groups”. It does not look like that to me here.

Ms Morris: The commission used to have the family living initiative and the community living initiative —

Ms Shapland: And LAC funding.

Ms Morris: Yes; and LAC discretionary funding. They were small packages of up to \$20 000, heavily promoting the planning to look forward to what was going to happen, using your informal networks around you—your neighbours, cousins, aunts, friends—in forming part of your support network. That money has ceased and has been forwarded to My Way. Those small packages of \$20 000 are now no longer in existence. I am not sure what other groups of organisations or funding may be available because, as far as I am aware, basically it is the CAP round or it is self-funded.

The CHAIR: That is certainly not the evidence we got from Dr Chalmers. He said, “Oh, well, people who missed out got these other packages or something offered to them.”

Ms Morris: Unless they needed temporary emergency funding. And that is what —

The CHAIR: No; it was not put on that basis.

Mr Granville: An option of \$20 000 worth of support when your son or daughter are looking to move out of home and have their own life is not a viable option. Some families do accept smallish packages.

Ms Morris: Because better something than nothing.

Mr Granville: All it does is delay families in crisis.

The CHAIR: It is not an alternative, basically; it is a stopgap.

Mr M.P. MURRAY: I am trying get my head around this. What crossovers are there between disabilities and, say, aged care? I am from a country town, so we do not have a service for

everything, so you can mix and match and get sent in, if you are lucky. I am trying to work out whether there are any cross-subsidies to be able to take someone who has a disability into, say, a high-care aged home. Does that happen or are you completely separate?

Ms Buchanan: It does happen, but I might let either Sue or David talk about that.

Ms Shapland: A lot of people end up in aged care by default because they have insufficient supports in the community and, ultimately, their health decreases and they end up in hospital. If they have not already had a CAP application in, they would not even be considered for any funded accommodation options, so by default they get ACATed and sent to aged care. I actually prepared something around this because it is a bit of a passion of mine. Experience shows us that most aged-care settings are simply not suited for younger people; that is, under 65 or, dare I say, 70, as 70 is the new 60 —

The CHAIR: That is a relief.

Ms Shapland: We are going to have to work till we are 70!

Most are not suited for younger people, particularly with complex care needs, especially those with acquired disability due to accident or degenerative neurological conditions. Most people with MS and a lot of other conditions will tell us that they would rather die than go into aged care. Without sufficient funding to support their increasing care needs at home and ability to access appropriate 24-hour supported accommodation options when needed, providing care and security, nursing homes may well be their fate. Many never get the opportunity to go into CAP. They go from hospital into a nursing home. Many others simply continue to fail the process. I have an example: Bob was diagnosed with MS in 1998 at the age of 36. His disease was progressive and by 2008, he had lost his relationship, his job and his mobility. In a wheelchair and experiencing the embarrassment of double incontinence, fatigue and difficulties with his activities of daily living, we lodged a CAP application for a care package, requesting \$37 000. HACC and the MS Society services were in place but becoming increasingly inadequate. Bob continued to deteriorate and developed trigeminal neuralgia, an extremely painful condition of the face, triggered by eating and drinking. He also experienced significant side effects from the medications he used to treat that condition. From 2009 to 2012, he had numerous hospital admissions and we were able to place him in and out of our residential respite home because his poor nutritional status and immobility were leading to diminishing health. In late 2012, the CAP was updated, seeking funding for a high-support accommodation option as he clearly needed access to 24-hour care and support. If support failed to turn up, he was found sleeping in his wheelchair and often sitting in faeces. Bob was admitted to hospital for surgical cleaning of a pressure sore and with no funding through CAP, had an ACAT assessment and was transferred to a nursing home in July 2013. He became increasingly depressed and teary, wanting to go home. Sharing a four-bed room with elderly men was distressing for him. Sadly, Bob died in October 2013, aged 50. We withdrew his CAP application. Funds dedicated to supporting younger people and aimed at preventing entry into aged care and facilitating relocation for those who have entered aged care into more age appropriate high-care supported accommodation options need to be ongoing, not released approximately every 10 years, as previously with targeted commonwealth funds. In our experience, cared for in the right environment, age appropriate and with staff with the right skill sets, younger people age in place and die with dignity. Growth funds need to be ongoing or we continually try to play catch-up.

[10.50 am]

Ms Buchanan: And there is many a sad story like the one that Sue has shared with us. An 18-year-old that an aide used to support had a very sad accident on holidays and went straight from hospital into nursing care. He was 21 when he moved into a nursing home. He could not do anything for himself. To say “yes”, he was able to open his mouth slightly to indicate a “yes”, and to say “no”, he would cry, and that was the only control he had over his body. Sadly, in the nursing home there are a number of other people very different to young Kell who needed support. A number of those

people, sadly, had had a degree of dementia. One of the ladies with dementia developed a soft spot for this young man and felt that she could support care for him. With her condition, she did not understand that the young man could only swallow food that has been pureed to almost a thick liquid. He could not chew; he had no chewing muscles. So he existed on a diet of slop, basically. But, like all young men, the lady thought that young Kell would love chips from the canteen, so she would go and buy potato crisps and give them to him, and he cannot chew. So he was often getting pneumonia because the pieces of chip that she crushed up and put in his mouth will go straight to his lungs. The only way to keep him safe from a very well-meaning co-resident was to lock him in his bedroom. This guy, he cannot call out, he cannot unlock his bedroom, he cannot say, “Hey, I need the bathroom now” or “Hey, I’d like to watch telly” or “Can you change a channel” or “I have an itchy head.” So he would stay locked in his bedroom between meals where someone will go in and give him his slops for his meal, and he really existed in his bedroom with the door locked. Sometimes someone would remember to put the telly on. I do not know whether he wanted to watch *The Morning Show* or not but that is what he would get. And that was his existence, because he did not have any alternatives for funding. There is many a sad story like that of younger people with disabilities living in aged-care facilities.

The CHAIR: And we have got Brightwater coming in after you, and of course I was talking to Dr Flett the other day and she said, “I think I’ve got about 80 in that sort of a category.” And you are right about the motor vehicle, you know, a lot of them are acquired brain injuries. If they can at least be sorted, that then does open up resources. There is just one last question I want to ask. Under the NDIS model and the My Way model I understand you deal with an individual who assists your plan, and that is just sketchy how that is going to work, I understand. But do you think that is a backward step in terms of not having a multidisciplinary team maybe looking at your needs, or, I mean, how do you all assess how that is going to play out?

Mr Simpson: It is interesting. The National Disability Insurance Agency started off with, I think, a very ideologically based position that service providers should be kept right out of the planning process. And, you know, it is for a good reason that it is about the individual and their lives and not wanting to see them influenced. There has been a lot of pressure from the sector, particularly through NDS, to say, “But, look, it’s people in the sector who often have the expertise and knowledge of the individuals who can help to inform that process.” What was being found was a high proportion of plans were having to be redone because they were done on insufficient information. So, there has been some movement in that from the National Disability Insurance Agency but with the consent of the person to involve the agencies. But, I guess, the short answer to what you are saying is absolutely.

Ms Buchanan: Yes. The reliance on the skills and knowledge and capacity of one individual in planning with someone for their life is always fraught with risk.

Ms Morris: We have parents that commented that we know more about their family member during that day-to-day care that we provide than what they do because they are with us. It is like a working environment: they have replaced school with coming to an option in a day service. So they are with us for maybe 30 to 35 hours a week and their parents may see them for an hour or so or a couple of hours into the evening before they start their night-time routine. So whilst I appreciate that it could obviously be misconstrued and misplaced in some organisations, I would very much like to believe that that is not the disability sector in WA. We are all here for the person with the disability. You know, I think I could speak for the entire sector and say that none of us would cross any of those lines for the procurement of the piddly amount of dollars that rarely covers the support and skills that are required to actually give these people quality of life.

Ms Shapland: There are also a whole raft of issues around people with cognitive impairment, people who are in denial of the level of need and just people who really do not want to spill their life story to someone who is not known to them when they actually have been engaged with a

provider or a number of providers using a multidisciplinary approach over a number of years. So, we do continue to have concerns around that assessment and planning.

Mr Granville: And, sadly, there are situations that one would look at with someone being referred to the State Administrative Tribunal and guardianship where there are different interests sometimes being served.

Mr Simpson: I think it is important to say in that regard that the whole philosophy of empowering people with disability and putting choice and control in their hands is one that we will support, but to ignore the expertise of people around them who know them well is just too simplistic.

Mr C.D. HATTON: I guess my question is directed to you, Terry, but I am quite happy to hear from the panel then. How do you think we compare with other states? I ask you, Terry, because as state director you might have more comparative information. How do we compare in disability provision, do you think?

Mr Simpson: I think we compare fairly well with other states. We do not, according to the last data I have seen, have the highest per capita allocation of funding but we are up there among those that do, and we have been a leader among states in terms of person-centred approaches. So, all in all, I think the WA disability system is one that does compare well if you look nationally. But nationally, though, there is the same problem that we have been talking about in WA: insufficient funds so that people are having to compete from a limited bucket. And lots of people with extraordinary needs are going without funding, and the effects of that are really destructive.

The CHAIR: If we had a transport accident commission such as Victoria, that would be an improvement, as I understand it.

Mr Simpson: Yes.

Mr Granville: One last grenade I would like to just lob, sorry, and it was touched on indirectly by Tony, is housing. So, accommodation support packages definitely need additional growth in that area. But there needs to be appropriate accommodation, bricks and mortar accommodation, and the range of models from shared accommodation to individualised to maybe clusters. There has been funding in the past but I think that is all committed. It is not just WA that is experiencing this. But there is an unmet need in appropriate bricks and mortar as well.

Mr Simpson: Yes, and I think what is important in all states is, as the NDIS rolls out, that the state commitment to providing accommodation for people with disability is met. There has been a three-year funding program of disability housing, which concludes at the end of this financial year. Again, the forward estimates do not have any further provisions —

The CHAIR: It is very depressing when you see like a little blank white box with nothing in it.

Mr Simpson: Yes; and the two go together. There is no point, if someone can finally get through the vagaries of the CAP process and actually get some funding to support them in independent accommodation, but then they cannot get housing.

Mr Granville: Yes, managing on \$400 a week disability support pension and paying \$350 a week in rent.

Mr Simpson: Yes. So, in order for the whole thing to work, the matching of the disability support funding with adequate housing is really essential.

The CHAIR: I am sorry that it has been so brief and certainly I believe —

Mr M.P. MURRAY: Can I squeeze one more in? It is a little bit different. It is about guardianship. You brushed on it just briefly about the individual home and the rights to have their say. Previously, there was an assessment about whether you were a suitable guardian or not; you went to the SAT area. Is that still the case? I have not heard if it has been wiped off, you know, about assessment.

[11.00 am]

Mr Granville: It still exists. There is still the State Administrative Tribunal for public guardianship.

Mr M.P. MURRAY: What is the time factor for the review to be held? Is it a five-year or a two-year or something like that?

Ms Shapland: I think it depends on the circumstances of the individual case.

The CHAIR: And you can go back and get it varied from time to time.

Ms Buchanan: Yes. It varies depending upon the individual situation.

The CHAIR: Thanks very much. It has been really valuable. I am sorry we have rushed you. Just so that your expectations are reasonable, can I say that this is not going to be some great magnum opus that people refer to in years to come; this is a short, sharp inquiry to get some idea of benchmarking how we are so that we can consider, firstly, how we will cope between now and when NDIS comes in and whether, when NDIS comes in, it is at least up to existing standards, if not better. This is really for us to get a picture in time of the state of play. By definition, our report will come out in May, but it will be a reasonably narrow scope.

Thanks very much. I just need to read this statement. Thanks for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 days from the date of the letter attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. Should you wish to provide additional information or elaborate on particular points, please include a supplementary submission for the committee's consideration when you return your corrected transcript of evidence. Thanks for coming today and keep up the good work everyone.

Hearing concluded at 11.02 am
