

**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, 4 DECEMBER 2013**

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 10.04 am

Mr CHRISTOPHER JEFFERSON,
Executive Director, People with Disabilities (WA) Inc, examined:

The CHAIR: Good morning. Thank you very much for coming.

Mr Jefferson: You are very welcome.

The CHAIR: On behalf of the Community Development and Justice Standing Committee, I would like to thank you for your interest and appearance before us today. We have just a couple of formalities we need to go through before we start the hearing proper. The purpose of this hearing is to assist the committee in gathering evidence for its inquiry into accommodation and intensive family support for people with disabilities. You have been provided with a copy of the committee's specific terms of reference.

Mr Jefferson: Yes.

The CHAIR: At this stage I will introduce myself and the other members of the committee present here today. I am Margaret Quirk, the chair. I am the member for Girrawheen. On my left is Dr Tony Buti, who is the member for Armadale; and on my left is Mr Chris Hatton, who is the member for Balcatta. The two other members are the member for Collie, Mr Mick Murray, and Mr Ian Britza, who might, if they can get away from other commitments, come in later. We are a committee of the Legislative Assembly of the Parliament of Western Australia. 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 you to provide evidence on oath or affirmation, it is important that you understand that any deliberate misleading of the committee may be regarded as a contempt of Parliament. This is a public hearing and Hansard over there 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. Have you completed the "Details of Witness" form?

Mr Jefferson: Yes.

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

Mr Jefferson: Yes.

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

Mr Jefferson: Yes.

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

Mr Jefferson: No.

The CHAIR: Excellent. Perhaps to start with, if you can tell us a bit about People with Disabilities and what your organisation does, that would be helpful.

Mr Jefferson: People with Disabilities (WA) is the peak disability consumer organisation. We are a funded advocacy organisation, providing both systemic and individual advocacy. We also run a self-advocacy group. Our funding comes from both the state and the commonwealth.

The CHAIR: And what are the most common issues that you are required to advocate for on behalf of clients?

Mr Jefferson: That is quite a difficult one. Certainly our work relates to education, to employment, particularly to services. Health has been a big part of our work this year, but certainly the relationship between the Disability Services Commission and its branches, helping people just manage that interface.

The CHAIR: As you are aware of our terms of reference, can you maybe outline what sorts of issues arise in the CAP process for People with Disabilities?

Mr Jefferson: The CAP application is a part of the process that starts, I guess, with people having to provide evidence that they are eligible to receive services. That can be quite a lengthy process in relation to people who have an intellectual disability or cognitive disability. People have to prove, no matter what point in their later life, that that condition existed prior to the age of 18. So there are often some real difficulties with people in establishing eligibility, even though it is widely recognised that the person has autism perhaps. Once you have managed to get through the eligibility criteria, you are then able to access three levels of services from the Disability Services Commission. The first part will be general advice and maybe signposting to services that might be able to assist you.

[10.10 am]

The second part may involve you having access to a local area coordinator so that you have got a face-to-face opportunity, I guess, to discuss your circumstances, and I think you will be encouraged there to problem-solve yourself and find assistance within the broader community—services to which you and I might have access, not disability specific. Then there is level three, where you require the services of the Disability Services Commission. That might include direct support work, for example, or aids and equipment. To get access to support you in your family home, as a person with a disability, you have to apply through a combined application process; that is how it is described. That is the same process that is used also to apply for accommodation support funding and also alternatives to employment funding. You complete a form. It is advised that that is signed off by a local area coordinator, and then that form is forwarded to the coordinators of the application process, who are Disability Services Commission staff. So it sounds pretty straightforward, but the CAP application process is one that is in a context of limited resources. So, to be able to access any of the funding through CAP, you have to evidence that your need is greater than the need of another person with a disability, or one family has to pitch effectively against another family who is affected by disability, and so it goes. We have advocate versus advocate, we have LAC versus LAC, and all the combinations between.

The process is one that if you are going to have a successful outcome, you have to put forward a case that results in more points. If you were a 70-year-old mum who thought it was maybe time that your 50-year-old son started to plan for his future, you would be filling in the same form that is being filled in by the 30-year-old professional who has got access to an experienced LAC, perhaps who is aware of advocacy organisations and some very skilled advocates who are able to—I think manipulate would be too strong, but be able to load an application in a way that could be favoured by the scoring process that is in place.

The CHAIR: I have had it said to me that the system is almost skewed for people having to exaggerate their situation and escalate it application after application, so if they are unsuccessful, they will then next time try to, if you like, beef it up or maybe put the worst-case scenario in just because they missed out the last time.

Mr Jefferson: The process would encourage that kind of behaviour, and we are certainly aware of cases where that has taken place, and I think to some extent, as an advocacy organisation, we have probably colluded with that to a large extent. It is very difficult when you are working with people who are quite clearly in desperate crisis, I guess, to not work in a way that is going to help them achieve the outcome that is going to work for them. It is very difficult to disregard all of the other people who are involved, I guess, in that same application process, because those numbers run into

hundreds and hundreds of people who are applying through this process for limited resources without us having a really clear understanding of how the scoring works. That does not appear to be a particularly transparent process. So what we find is that people who have made applications and seen the result and changed their next application and received a better outcome have then learned perhaps there is some value in using a similar technique. So one of the things that appears to be obvious is that if you are homeless, you have got much more chance of receiving accommodation support funding. Most parents do not want to put their son or daughter on the street to be able to achieve a positive CAP outcome, but if you were prepared to do that—if you were prepared to say, “You can’t live here anymore; off you go”—then it is highly likely that if that was indicated in your CAP application, you would receive more points as a result of that. As a result of that, with certain people, you could imagine that that knowledge could lead to, I guess, some very deliberate acts to try and affect the outcome. And we see that really disadvantaging the 70-year-old mum—if I use that 70-year-old mum as an example—who would perceive that as being totally shameful. The people of their generation would clearly judge and not see that as being, I guess, part of a process to achieve a positive outcome. That might be more acceptable for younger parents who would see that as a radical approach to achieving a good outcome.

The CHAIR: Can you give us an example of a case that you are aware of where someone missed out that you thought was worthy through the CAP process?

Mr Jefferson: I can, but in picking out one case, it is kind of doing an injustice to the ones that we do not know about.

The CHAIR: No; I just think we need a bit of a baseline to find out what sort of cases are falling outside the cracks, if you like.

Mr Jefferson: Okay. I recently, I think for the last funding round, assisted a person who had Down’s syndrome, and he was just under the age of 60, so in my view he is a bit of a hero because most people with Down’s syndrome do not achieve that. He was one of the few people I have met with Down’s syndrome who has to use a wheelchair for mobility, and he has really been struggling with his weight. And you could see how his circumstances had deteriorated a lot, but there was no, I guess, compensation with regards to the level of support that he was getting. So it meant his life was incredibly restricted. I do not think that man is going to live much longer. I am no medic. He has achieved amazing things so far, but not being able to get out and about, being in his house more often than not, having nothing particularly to look forward to because there was no support to provide anything other than that basic meeting his personal needs, I felt that would have been a huge investment. For me, he was a bit of a hero. Maybe he has got two to five years left.

The CHAIR: So that is a case where you were seeking additional support; you were not seeking accommodation?

Mr Jefferson: That was a case where we were seeking additional support funding because he already had some level of support funding, because the CAP process is used not only for people who have no funding, but for people whose circumstances change. I would not like to be in either space, to be fair, as a family member or a person with a disability, because having some support that is inadequate or having no support, which is obviously inadequate to meet your needs, I guess is equally demanding.

The CHAIR: I think somewhere we have been told that the average time to receive some sort of assistance was two years. Does that sound about right?

Mr Jefferson: It may well be the case.

The CHAIR: I got some noes in the audience there.

Mr Jefferson: I guess the issue is not in relation to what the average is, but we have to consider who are the people on the list. So, if you as a mum are talking to your son about maybe him having similar life stages to the rest of his siblings, so at 25 you start up a conversation about, “Is it time for

you to think about maybe leaving the family home, maybe sharing a house with some mates, and start that next stage of your life?" you cannot have that conversation with any confidence because you would not know when you could achieve funding. So I imagine that lots of the applications on CAP are from people who have put in a CAP because they know there is going to be a delay, and if you are not living in a crisis and you are not homeless, then it is going to be quite a lengthy delay. But, a bit like getting on the housing list, you have to put your name down at some point or you are never going to achieve a house, even though you know it may be many years in advance.

[10.20 am]

The CHAIR: So there almost needs to be some sort of triage system because you have got two lots competing. You have got those where maybe the parents are elderly and themselves not well as opposed to those that put themselves on early and say, "Well, we know we're probably going to have to wait six or eight years. We'll put our names down now." Now, they are effectively not equivalent, are they?

Mr Jefferson: That is right. There is quite a difference. You have got one family who wants to plan and you have got another family who are trying to cope, often in extraordinarily difficult circumstances.

Mr C.D. HATTON: Thanks very much for being here today. Most cases or files that you would attend to are obviously very genuine, and I would not dismiss that, but is there much of a burden on the application process due to people who have unrealistic expectations with disabilities?

Mr Jefferson: In my experience, and certainly talking to my advocates, there tends to be a tendency for people to underestimate what the day-to-day needs of the son or daughter are. There was a very recent conversation where an advocate described being with a parent having achieved some funding, so it was indicative that she would receive funding, and going through an options exploration process with members of staff from the commission whose job it is to do that, where they were completing a form called an ERSSI. I am sorry I cannot tell you exactly what that means. I know the last word is "instrument". And during that conversation, when asked, "Is your son able to shower?", "Oh, yes" was the response. So the advocate said, "So he jumps out of bed in the morning and goes and has a shower", to which mum says, "Oh, no, he doesn't get out of bed unless I wake him up, and he can't go in the shower unless I run it because he would scald himself." So I guess our experience is of steeper variations between those who are very aware, and I guess a lot of that is to do perhaps with their education and their awareness of how you need to talk to professionals within the disability sector, and even using their jargon—the language that they use. I think some people are advantaged in that. Certainly, older parents tend to be a bit reluctant, I guess, to sometimes even breach the rights of privacy that the son or daughter have got, so they do not really want to tell other people about private things, about matters that relate to bodily functions, for example, so they often have to be guided and encouraged to be honest with that. And it is very important that they do, because the support service that will be negotiated between the commission and the non-government providers, for example, will be based on, if you like, that evidence that informs that assessment process. No, I would say if there is anything we have got, it is low expectations that people with disabilities have around themselves—I guess that is societal lower expectations—and it would appear that they carry that and that comes out when people speak about what they want. Very few people say they want to go and swim with dolphins and go to Disneyland and can that be part of the package, although I understand that is becoming part of the conversation about My Way and the National Disability Insurance Scheme.

Dr A.D. BUTI: It is hard to imagine unrealistic expectations. I would have thought in a state as rich as Western Australia that everyone should have a reasonable expectation for accommodation, so I am not sure about unrealistic expectations. And I think you are right that people do underestimate the situation. You talked about, in the end, it becomes a competition.

Mr Jefferson: Yes.

Dr A.D. BUTI: Under the CAP system, are there any categories? For instance, there is a certain amount of people with a certain disability who will be housed, and then it moves on to another disability, or there are no categories that they try to fill?

Mr Jefferson: I guess one of the challenges in coming today was getting access to factual information. There are lots of things that I believe I know about the system, that I understand that I have been told, but when you go to confirm that in relation to policy that is publicly available, that is actually quite a challenge in relation to the way that some parts of the Disability Services Commission function. So I am not sure how many people are involved in the process, which is described as an independent process, with regards to assessing CAP applications. I do not know how many of those people are actually employed by the Disability Services Commission compared to from the general community. I do not know how the scoring system works. I indicated that homelessness seems to achieve quite a lot of points, but I have not read that anywhere; that is just as a result of experience. So, often in providing answers, I am challenged by the non-availability. Look, I think I am pretty good at accessing website information, and I have got some people who are pretty good at doing that, and I am quite good at asking questions. I think we could do much more in enabling effective communication of these things to people with disabilities and their families.

Dr A.D. BUTI: So basically you are saying that there seems to be an issue with transparency in the system.

Mr Jefferson: That is certainly reflective of not only our advocacy organisation, but certainly other advocacy organisations I talk to. If I can give an example, and I do not think it is equal amongst us all: the CAP application process reporting has changed over recent months, and I was happy to accept the director general's reasons for that. There was lots of information coming from it that he felt took people away from the important information, which was that so many people achieved a positive outcome from the funding that was available.

The CHAIR: And so what information was no longer being disseminated that he said distracted or —

Mr Jefferson: Certainly, the overall number of applications was a thing that everyone looked at, so when you heard that eight people had been successful, people tended not to celebrate those eight people's good outcomes; they tended to then talk about the 392 other people that were left waiting.

The CHAIR: So is that information no longer publicly available?

Mr Jefferson: Not in the same way that it was before.

Dr A.D. BUTI: That is amazing.

The CHAIR: That is extraordinary.

Mr Jefferson: I think the difficulty with the information was—I have some sympathy with it. I mean, I would have thought the best outcome would have been if they produced more information. So, if you could actually say of the however many outstanding—the hundreds of outstanding—applications, they relate to, and you could maybe have some demographic groups that relate to that. We know that carers and organisations that are concerned for more elderly parents would certainly like to see those stats include some reporting in relation to that particular cohort. I think that, for myself, I am always really interested in people who have got comorbidity, particularly mental illness and intellectual disability as a dual diagnosis. I think that it is a group that are particularly vulnerable and are particularly difficult to find appropriate services for.

The CHAIR: Mainly because they do not fit in one box or the other, or their needs are more complex?

Mr Jefferson: Probably both of those things, but my biggest concern relates to cost shifting. So it may well be that if somebody with that level of complexity has a service that costs \$500 000 a year,

I am sure that the Disability Services Commission would rather that the health commission provided that funding, and vice versa. I am not saying there is any level of horse trading goes on —

The CHAIR: No.

Mr Jefferson: — but I think that must be a reality for any kind of —

[10.30 am]

The CHAIR: Let us put it this way: there are incentives for them to choose someone else who has less complex needs in those cases.

Mr Jefferson: But the CAP application process should disallow that if it is an independent process that can be scored, and it is scored, but I am not sure that it is independently verified, so I am not sure that anybody kind of sweeps in behind that as part of a quality evaluation process, for example, that actually tests whether a process that is indicated to be independent—I imagine people are good, honest people doing their best to score it, but it may well be that some people within that process perhaps do not understand it in exactly the ways the other parties do. I do not know what happens in the event, for example, that one person scores highly with regards to one situation and another person scores lowly, and whether there is any, I guess, process to investigate that and perhaps offer additional training to those two parties who have achieved these very different outcomes. I just do not know. It may well be there; I do not know.

Dr A.D. BUTI: Is there any periodic evaluation of the CAP process?

Mr Jefferson: I do not know.

Dr A.D. BUTI: So the industry does not know. Basically the industry that you work in and your clients do not know whether the CAP process is evaluated.

Mr Jefferson: It is certainly not the case that I know it; it is certainly not the case that people with disabilities generally—it is not a conversation we have had particularly. I am not aware that it is. It may well be, but I do not think that information is publicly available. I guess, when we are talking about demographics, it would be interesting to know which of the people who made a CAP application did it as part of a forward-planning process and which of the people made that application as, “My needs are immediate; we’re at breaking point now.”

The CHAIR: Exactly.

Mr Jefferson: I think, unless we know that—and I think if that information was publicly available, it would be much easier politically to, I guess, get government to look at that. At the moment, all of the advocacy organisations fight for unmet need. We know it is there. We talk to people who are really suffering on the wrong end of this, but we do not know what those numbers are and we do not know if everybody who is in difficult circumstances applies through CAP, because they do not believe it is possible to succeed, for example.

Dr A.D. BUTI: Yes, that is the other thing, the people that do not apply because they do not think there is any hope. By the sounds of it—this is actually quite absurd that we do not know how many people apply, so we do not know the percentage of the success rate. Then we have the other avenue, which is a lot more difficult, obviously, which is how many people do not apply because they do not feel they have got any hope? The situation, therefore, is probably a lot worse than anyone can actually recall.

The CHAIR: So, for example, you might have a situation where someone is cared for by their parents, until they get too old to be able to cope anymore, so they are effectively hidden statistics almost until the stage when they do need quite acute intervention almost.

Mr Jefferson: If I could just speak to that, yes, that is the case. But that particular scenario is a really interesting one. We know anecdotally that in those situations where you have got a particularly elderly parent, the carer role changes, so that we have got situations where we have got

people with an intellectual or cognitive disability effectively supporting mum, who has looked after them for years, to continue. I mean, we have all heard the horror stories of the parent who has died and the person with the disability has not known how to—and has just sat with mum while mum slowly —

The CHAIR: Decomposed.

Mr Jefferson: Yes. That is a particularly difficult situation. We are also not sure as to what the older parent actually knows. We do not really know how many people are out there where mum has done this forever and has not actually had any direct contact with the Disability Services Commission because mum and maybe an auntie have provided that support. Maybe they are known to the carers, so they have got some kind of peer support, and they have conversations, but will never make that application because they are not prepared to live with the shame of having put their son away, even 50 years on when that is no longer a phrase that you would ever accept as appropriate now. But with that generation of people, that shame is still very real.

The CHAIR: The other thing with the CAP system is that it is really a yes or a no, is it not? For example, if you use the elderly parent scenario again, they might be able to not send their son or daughter off to accommodation or whatever for a couple more years. They could postpone that if, for example, they had more respite. But, as I understand it, it is sort of, “No, your application is not successful”, or, “Yes, it is”, or is there some way that the commission says, “Well, we can’t manage this but we can give you some extra respite?” I am getting noes from behind you.

Mr Jefferson: Up until the last CAP round, I kind of thought that is how it must be. I think what is important here is that I have the answers based on my experience.

The CHAIR: Yes, that is why you are here.

Mr Jefferson: That is one of the reasons I employ extraordinarily experienced people within the organisation, because they know so many people and they have come across these different situations. I guess, for me, I kind of take it at face value, until a case is brought to my attention. But, yes, I am pretty sure it was the last CAP round, a family was indicated that they could receive—they did not get —

The CHAIR: What they were asking for?

Mr Jefferson: They did not get the outcome that they were asking for, but they got offered some assistance to take their situation forward and to be assisted to address some of the very clear difficulties they were having.

The CHAIR: We will clarify that with the commission. The other issue that I have frequently been told is people say, “Look, we understand that there is so much unmet need and we can soldier on for the time being but the future is so uncertain. If we could be given a clear date, that we might have something in three years or five years, we could cope.” It is the uncertainty of not knowing if and when something will happen. That is one of the major issues.

Mr Jefferson: It is a terrible burden on people, but we need to understand that we have limited resources and the money that is available for new applicants to the CAP round, as I understand it, comes from two places. One is that from time to time the government makes available additional funding, which is fantastic, but the other money comes through what is described as natural attrition, which is a term that appears to cover the funding that becomes available as a result of a person with a disability who is supported passing away, or a person receiving funding from the Western Australian Disability Services Commission moving out of state. I cannot imagine there are too many of those. And there is a third potential, which is when people, having received their money, have made good progress and feel confident that they do not need that level of support and so return some of their funding to the commission. I have never known that to happen. I imagine it may well have happened, that third one, but there seems to be a genuine fear that if it went back and then the person with a disability’s circumstances changed and they perhaps became unwell, they

would have to go through the CAP process again, which had maybe been a two or three-year wait in the first place, so there is no kind of incentive to do that; in fact, there is probably a disincentive. So you do not really know how much money is available each CAP round. Up until, I guess, that process is gone through, you do not know how much money has become available through that attrition although you would be aware of any additional funding that has come through the government. So, for me, that is obviously the safest way. If we are going to meet unmet need, we need to get more money available in that CAP round. I think there is lots of money in the area of disability, if you like, with the money that has been raised through charity in the name of people with disability, in the money that comes into the commission in the name of people with disability. I think there are some questions to ask. Is that money used most effectively to meet the needs of desperate families on the CAP list or is it being used for some purpose which has value, but is it of as great a value as actually meeting the unmet need?

[10.40 am]

The CHAIR: Can I be really bold and ask: for a purpose such as?

Mr Jefferson: You could ask that question. Look, it may be that you just need to take a little piece from across all departments. It may be that there is a particular piece of work that is being done that draws a lot of that resource that maybe cannot be justified compared to the anguish and pain of, first of all, the person with a disability and their families. Because I think sometimes in this conversation, you know, the person who makes the application is usually a family member with the support of somebody else. The person who does the advocacy, picks up the phone and makes the complaint, is usually a family member, but at the end of the day the person who is suffering as a result of the lack of—the bottom line is, it is the person with a disability that pays the heaviest price, and I am not disregarding the amazing things that family carers do, but it is the people with disability that we are actually here, I guess, ultimately to provide for.

The CHAIR: By the sound of your voice, and I understand from the background we have been supplied, you have worked in the disability sector in Scotland?

Mr Jefferson: Indeed.

The CHAIR: What are the sorts of differences? Is there anything that is done there that you think would be readily adopted here or vice versa?

Mr Jefferson: Okay. I spent 30 years doing voluntary work and I think it is really important for my background. I learned in three different areas. I learned as a result of going to college and being brainwashed by social work and not really being very good with all those theories because I have spent so much time with real families, hearing about real lessons that they had learned. I spent 30 years doing that and I met some amazing people. My formal education, I feel, came from my informal time with them. But I also did a 24-year career with, their term, the leading organisation supporting people with an intellectual disability in Scotland. I then came to Western Australia, where I had heard great things about what was being provided, and I went to work for a service provider and spent 18 months there as an accommodation manager. It would be fair to say that my experience reflected perhaps the theory of what was being made available in WA compared to the reality of that, and I learned some hard lessons about the hard lessons that people with disabilities are experiencing. I really struggled with the group-home model and how that was seen to be a methodology, an approach, that could achieve good outcomes for people. I had spent 10 years working in that space, thinking I was doing the right thing, helping people not achieve good outcomes, and I thought those lessons had been learned in Western Australia. I thought those lessons had been learned in Canada. That was me all full of reading I had done about international best practice. So I was really disappointed when I got here, to be fair, and ultimately that is why I joined an advocacy organisation because I believe that it is the reality that we need to cope with in Western Australia; what is actually happening for real people; the impact of limitations placed on people with disabilities, as a result of being in a poorly resourced, and I do not mean with regards to

money—I think there is an amazing amount of money being spent—but poorly resourced in relation to frontline staff and middle managers understanding what contemporary practice is in relation to people's right to direct their own lives, in people's right to not experience restricted practices, in people's right to not have to be locked in a bedroom to protect them from the person with the big support package who has to live with them because that is the only way that the financial model of the group home can work.

Dr A.D. BUTI: So, Mr Jefferson, if someone asked you how could the CAP process, just the process, at this stage could be improved, what would be some of your recommendations or suggestions?

Mr Jefferson: I would recommend that they actually make the process available. If people want to receive commentary on something, if they want advice to improve something, then they really have to let you know what it is. You have to have access to the detailed workings of it. You want to know who else is sweeping behind, providing an evaluation of that process, an independent evaluation of that process, because quite clearly I am going to struggle to provide an independent voice, because, you know, this stuff really matters to me because I spend a lot of my time with the people who are affected through our unmet need. I think the commission are very good at consulting outside consultancies when they want to have a look at something. I would have thought that certainly with the CAP process they could have done something similar. They may well have done and they may well know what the outcomes are—we do not. So for me it is just a case of “let us know what it is”. Let us have a conversation about identifying the demographic groups within the information that has been made available so that can inform the advocacy of the families, of the sector, even of disability support organisations. Because one of the things to remember here is that lots of the applicants in the CAP process are disability service providers, so they are filling forms in on behalf of people they provide the support for because they want additional funding. They want additional funding because they cannot adequately support the people with the funding level that has been agreed, and that is a really important demographic, because when mum is not coping because dad has left or somebody has developed a medical condition in the family that means that family member cannot support the person with the disability in the way they used to, they are usually in a bad place. They are having a tough time. Just when you are at your lowest ebb you then have to start a process of filling in a CAP application form, and you are probably going to do that just as quickly as you can and get it filled in; you are not going to consult. Disability service providers have got people whose job it is to fill in forms, to support people to do that to maximise the likelihood of a positive outcome, and they may well have access to that anecdotal evidence that most of the advocacy agencies have got. They may well know how to, to use a term, load a form for a positive outcome. They want long-term recurrent—

The CHAIR: Security of funding.

Mr Jefferson: They want recurrent funding, but they have access to a process so that they can get non-recurrent funding, which is a process that families do not have. So if you as a family member are in a very similar situation to a service provider, as a family member you go—in fact, if your son or daughter is in accommodation support, you do not have access to an LAC anymore. When you get accommodation support funding, you lose access to your LAC. That is really important to remember. So what happens then is that the service provider contacts their service contract development officer at the Disability Services Commission and says, “We are really struggling with Billy here. We're having to commit loads and loads more hours as a result of his change in circumstances. Can we have some more money on a non-recurrent basis to get us through this difficult period—say six months?” So what happens is that the form is then filled in and it is sent to the service contract development officers, who then make a decision as to whether that funding will be made available on the non-recurrent basis for that period of time. What I find amazing about that process is that disability services is not contracting social workers, occupational therapists, or if they are, that is incidental to their role, so we have got somebody at the Disability Services

Commission who does not have that level of expertise being informed by a service provider about this terrible situation where they have clearly got a conflict and so they are making an application. They need the money. They are filling in a form and saying, “We desperately need this”, justifying that. I do not know if it is a form; I do not know if it is an email, but whatever it is, it is never seen by the family because it is never verified.

[10.50 am]

It is never seen by the person with the disability, even though it may well say very personal things about them. It might well describe them as having challenging behaviour or something that relates to their, you know, recently developed incontinence or whatever. They have got no opportunity to debate that. They have got no opportunity to say, “Hey, come on, that’s not me” or “That’s exaggerated” or “Why haven’t I been told that?” because of something a mum or a dad might say, or a guardian. So it is not a level playing field in that sense. For me, it cannot be like that. If that situation is going to continue and those people are getting access to some funding, I imagine quite a large amount of funding that can be diverted to the CAP fund, then I think that is something that should be debated. I do not think that is a decision that the Disability Services Commission should be making under, presumably, some pressure from the disability service providers. Clearly that is a system that works for them. They can get a rapid response to a crisis that they are struggling to manage. If you have got 500 clients, how often does that happen in a year? So if this is happening on a regular basis and there is this large pool of non-recurrent funding that is being accessed by service providers and that could be available to families in crisis, then I can only think that is something where we should all have access to a conversation, a dialogue, a debate about that.

Dr A.D. BUTI: A few things: how many advocates work in your organisation, and how much of your time percentage-wise would be spent on CAP application or accommodation needs in a year?

Mr Jefferson: The amount of time we spend on CAP applications is quite small. It is quite small because lots of people are making applications to get the support of a service provider. So if you have decided that you would want, should you be lucky enough to get your money, to be supported by an organisation like the Centre for Cerebral Palsy, you would probably have had a conversation with them and they have assisted you to fill in the form. So that is quite a common process, where you would align with a service provider before so you can get support that way. Lots of people have good LACs, local area coordinators, who are very prepared to assist in that process. I think it would be fair to say that we get the people who have failed to achieve after frequent applications. One recent case was where they had an LAC appointed very recently, and it is important that your CAP application is signed off by your local area coordinator wherever you are cared for. It is not a requirement but it is certainly a recommendation that you get that. So yes, an LAC said, “Well, I have just become your LAC. I really don’t know your family that well, so I cannot realistically sign it off.” We wondered if that application was disadvantaged as a result of that. So that was a case that came to us. The people who perpetually get the letter indicating that they have not got it are people who often get signposted to us in the hope that we can leverage that, and the only way we can leverage it is by helping them use the form and what understanding we have got of how you can achieve a good outcome. We do not spend a lot of time doing that, but what I would say is that we spend a lot of time on the telephone to people after the CAP round, counselling them, directing them to counselling services, somewhere where they can go and talk, to peer support groups for people with disabilities, so that they have got somebody to talk to about this, another long period of time where they do not believe that they are going to achieve, and then we have got carers who meet with other carers, who sit together and have a cup of tea and talk about how awful it is but taking some comfort from that. We certainly take a lot of those phone calls, particularly at the end of the CAP round—angry phone calls, upset phone calls.

The CHAIR: Is there other alternative sources of funding for people who are unsuccessful in the CAP round?

Mr Jefferson: Look, there are different forms of funding. I have already talked about the alternatives to employment. We have got the intensive family support and we have got the accommodation support. So they go through the CAP application. There is another opportunity. It is maxed and it is called community living. I am not saying that with great confidence. I believe it to be called community living funding, and it is an application that can be made. There is a particular panel meets to look at that. You put together a plan and you have to cost that plan at usually about \$20 000. I think you can probably max it at \$24 000 but you have really got to justify that expenditure. And it is about showing through that plan what great things you could achieve for yourself as a person with a disability, but also the pressure it could take off the family or opportunities for, I guess, family members to become more productive, because often families have to stop working. They become non-productive in that work sense. Their career is affected. So there is a small amount of funding for that. Beyond that, in relation to direct funding from the commission, no, I am not aware of that. Obviously through the commonwealth, people can sometimes get some assistance through HACC, but that is a very different type of funding for very different outcomes.

The CHAIR: NDIS is in bit of a flux at the moment, but how would you see—if the proposals that have been put up for NDIS, how is that going to alter what happens in WA or is it going to alter what happens in WA?

Mr Jefferson: Could I challenge slightly on the use of the term “flux”? I do not think the NDIS is in a time of flux anywhere in Australia as much as it is in Western Australia.

The CHAIR: Okay, yes.

Mr Jefferson: This has been a really challenging time for an organisation like ours that is run by and for people with disabilities, because we were given the opportunity to inform the development of the principles behind the My Way approach. We were incredibly supportive and remain incredibly supportive of those principles and them being infused into the way that services develop, both from a funding perspective and the outcomes that people could achieve. Then you start a campaign that you believe might take a decade to win, and suddenly within a very short period of time, the fight for a national entitlement scheme appears to be, in large part, won, and its principles were developed out of the 16-point set of non-negotiables that were put together by the leading advocacy organisations, people with a disability, consumer organisations. It was just like wow. Suddenly there was this massive movement towards choice and control, safeguarding, managing risk aversion and all the stuff that we have been struggling with over the years. We certainly have these two amazing strategies going forward. And we would have been happy, I guess, with either being adopted. We are now in a really complicated space, unfortunately. What the disability coalition asked for, which is a group of organisations, which is the advocacy organisations, NDS, the Western Australian Individualised Services, a group which is one of the leading mental health groups—so that is the disability coalition. What we asked the state government to do was to do everything that they could to influence the development of the national disability insurance scheme, and I think they have been brilliant and spent a lot of time and resources doing that, and we have been well represented by the Department of the Premier and Cabinet. Their people have gone out and really made a difference in the way that that has developed. We are really thankful for that. But at the same time while the Premier signed up to be a part of the national disability insurance scheme, we have only got a deal that is for two years, so all the celebration we did about having won the national disability insurance scheme is not necessarily true for us. But we take comfort from the fact that there is a commitment to long-term involvement.

[11.00 am]

So here we are. We have got two pilot sites coming up. They are both really exciting, both really interesting, and we look forward to the evidence that is developed about approaches for both people with disabilities and the people who are important in their lives, be that family carers, be that

husbands, wives, children, spouses, lovers or whatever that is. So we are very excited about that. However, there is going to be a massive investment in comparing the two sides. There is huge resource being taken to managing these two things going on at the same time. All the attention has been directed, both from Canberra towards, you know, this bit of country in the hills, and from the commission towards the My Way sites. So they have got some of the commission's best people doing that, and that has got to be distracting from the rest of the work and the day-to-day business. With the majority of people with a disability living in the rest of Western Australia, living in the massive remote rural landscape that it is, I am concerned that the resources are clearly shrinking at the Disability Services Commission. A lot of resource, time, energy and focus is going to be put towards the transition of 300 people from their services to the non-government sector, which is something I think in principle we support. However, we do not have enough advocates, to answer your early question, to match all of that, to keep an eye on all of that, to challenge with regards to all of that and to support all of that, because I think people forget that advocacy organisations do not spend their time throwing rocks. Certainly some of my advocates do, but on the whole the systemic advocacy that we provide, probably about 85 per cent of it, is sitting in groups, providing consumer input from a person with a disability's perspective. So lots of members of our committee of management, are members, people who have lived experience, family members, who are sitting on committees, groups and development organisations and boards of disability services providers, providing that input. Yes, look, we are super stretched, and if people only did what they actually got paid for, we would not be coping.

Mr M.P. MURRAY: Back a little way but about the grassroots of the whole system, the person concerned and the parents or the carers, and the use of the demographics, but what about the individual? I am hearing the big-picture stuff and I certainly understand the big-picture stuff is very difficult. I think it is far more difficult right back, and that is what we have to deal with in my office, right back to that, "I can't get this. I can't do that. I've been to my next level up and have been rejected." How do we get the service right down to the ground? As you come through you are soaking everything up, and you have alluded to that. Some people want to take their slice as each dollar goes through. How do we get the maximum dollar to the person that really needs it? That is what I am not hearing.

Mr Jefferson: I cannot answer it because I do not know. I do not know. I think you are absolutely right. I mean, this is a very large cake but by the time it gets to the person with a disability, we are talking about a few crumbs. Some people are very well catered for. Some people get access to really good contemporary services with adequate funding. I think that part of the battle is that mum over here is struggling and sees that and is almost jealous of that, if you like, and that is what they want, too. I do not know. If I can give you an example: if you look at the amount of money that is raised in the name of people with disabilities—in their name—by organisations by rattling tins, I imagine it is billions. I do not imagine it is just millions in Western Australia; I imagine it is billions. They do that based on whatever processes they use. So we get some sickly sweet advertising campaigns, where it gives the impression that people with disabilities are all under the age of 12 and absolutely gorgeous, and there is usually some really emotive kind of backdrop. What we have got there is loads of money coming in, and people with disabilities are not having any say and their families are not having any say with regards to how that money is being used. And they are charities who are doing this, who also act as service providers. So sometimes we have got organisations who are taking the dollar, and I understand it is about \$44 an hour in relation to every one hour that is provided in service, so the companies are taking their \$44 and they are going out there and saying, "Look, we're doing amazing things for these poor people with disabilities, these objects of charity. Give us some more for our pot", and the mum who is struggling who cannot get access through the CAP application process to the services that the government are providing, and often generously, cannot get access to the money that is coming through the decency and goodness of the Western Australian community through funding. It is very difficult for an individual to apply to Lotterywest,

but it is very easy for a disability service provider organisation to apply to Lotterywest and get big lumps of money. So how does the person at the frontline, that family at the frontline, get help in a way that is meaningful, that provides dollars to them, that they can control to buy what they know their family needs?

Mr M.P. MURRAY: That is where I am coming from.

Mr Jefferson: That is the hardest question. I do not know what the answer to that is. Clearly—I would say revolution, but that is not helping.

The CHAIR: International best practice: is there anywhere where you would say it gets it better than others?

Mr Jefferson: It would be fair to say I have a healthy cynicism when it comes to measuring outcomes. At the moment, if it comes out of Canada, it is international best practice. It may just be that the Canadians are very good at selling what it is that they do to people who want to fly around the world to attend international conferences.

The CHAIR: Oh, sprung!

Mr Jefferson: For me it is about your question. It is about getting the disability dollar to the person with the disability. Am I convinced that these statements of international best practice reflect best practice? No. Am I convinced that what works in Finland works in the Kimberley? No. I was going to be flippant there, but I am really struggling with it. International best practice says people with disability need to be in control. When we use the term “people with disability”, I do not mean, “and some parents”; I do not mean their carers; I do not mean their service provider. I mean that individual and the people they choose to be in their circle of support—they may well include their loving parents; they may well include their lover; they may well include their next-door neighbour or the guy from the local surf lifesaving club. But it is for them to decide, and until they are 18, it is for the parents to be a big part of that conversation. And sadly, it is often their guardian that is a part of that conversation, too. I see that as not always necessarily appropriate.

The CHAIR: Do I detect that you think there is a level of, if you like, paternalism in how we deal with people with disabilities here?

Mr Jefferson: I would not want to. Look, that is not exclusive to Western Australia.

The CHAIR: No, I know, but you certainly think in terms of decision-making processes and stuff that it is quite often people surrounding the person with a disability that have the loudest voice rather than—

Mr Jefferson: I did not realise there were so many things I had a strong opinion on. I actually think it is a really important area. It is not unique to the commission; it is not unique to government; it is unique to society. So I think at every level everybody knows what is in the best interest of people with disability. My next-door neighbour does not think I know what is in his best interest and I certainly do not accept that he knows what is in mine, but if he had a disability, I imagine that I would think I would probably have more right to have a say about his life than he had to say about mine.

[11.10 am]

Dr A.D. BUTI: Can I challenge that a bit?

Mr Jefferson: Please.

Dr A.D. BUTI: I understand what you are saying and we want to give autonomy, as much as possible, to people with disability, and yes, often it is family members that have the strongest voice et cetera, et cetera, but I do not think it is easy to delineate or separate that relationship, because often, for better or not, there is such a close, symbiotic relationship between the parent and the person with disability, so yes, we could say when they turn 18, the person with disability should be

treated like all other adults, but in reality that is not always possible, and the strains on a parent with a child with disability—it does not matter what age they are, they are still their child—is a lot different than a parent with an 18-year-old child that does not have disability. I think the difference there is because, of course—my own experience is, and you come from an advocacy perspective of the person with disability, and I understand that, but I am not so sure whether I would go as far as your views on that one.

Mr Jefferson: I am happy to respect your views. What I would say is that I am the parent of a 27-year-old, a 20-year-old and a 16-year-old, and it is not until you have a conversation with parents who have a child with a disability that you realise that actually you are both in incredibly tough spaces. Actually raising children and when they become adults is equally—and I think if you do the sum of taking raising a child with a disability minus what it is like just to raise children, I think you are left with something that can be incredibly demanding. It depends on your approach, it depends on how much family is around about you, how you are to have support, and all of those. There are lots and lots of different factors. What I would say is that when I talked about circles of support, I imagine most people with a disability would include their parents in that, most people would include their siblings in that, but we work with cases of significant intentional and unintentional damage to people with disabilities by family members in the name of their best interests, and we see damage being done by schools, principals, teachers, who do not accept the right of the parent of a child with a disability to know that person in a way that no other person knows that person and how those impairments impact on that person's life, some being disabling effects and some often being new abilities—abilities that you and I perhaps do not have. So yes, I agree it is very complex. This is not merely an advocate talking; this is a guy who has hung about with people with disabilities, enjoying being a part of their lives, that has kind of come to this conclusion.

Mr C.D. HATTON: Just on that point, and I was not going to raise it but now it has been raised, I have hung around in my previous life as a teacher with parents with children with disabilities in a classroom, which includes joining that up as a teacher every year, since you have those children in the classroom, and I quite often find it astounding how there is not a level in some cases, I would say, not all, of compassion and awareness of some teachers and the education system. Quite often I have heard mothers come to school crying just to get their child to school with disabilities, whether it be autism or physical or intellectual or another case, and I have got a class of kids to teach, but just looking out the window and seeing that parent and how their days starts, it is very difficult for me to comprehend what it would be like, and I have got four kids still at home. So I just wanted to touch on that point. But what I really wanted to ask you was that earlier on you mentioned about money not really being the major problem, and funding, although it always is, but possibly a parallel problem is the lack of skill or awareness of the bureaucracy who is making the decisions. Would that be correct? Look, I will ask you the question: do you believe there could be better outreach from the disability commission to your advocacy groups that you network with to have a common goal and to be aware of the processes and deliver more transparency and communication? Is the bureaucracy really getting down to you guys?

Mr Jefferson: I think the people who manage the CAP application process who are employed by the commission are very good professionals. I cannot really fault their job, and they work within the rules that they are given, as far as I understand the rules, and I think a part of that is I know those people and I have worked with them in other areas, so I know them to be people who would play with a straight bat. It is the process, I think, that brings about the challenges. I do not know who the people are who do the scoring process. I understand they are employed for a six-week process. They are paid to look at each and every application, so if there's 400 applications, they get paid to look at 400, and they score in a way that is true and honest. I do not know who they are, and I think that is part of protecting that process so that people cannot be got at. But, as I said earlier, I do not know how many are employed by the Disability Services Commission and therefore would have the potential for a vested interest or could be influenced, and how many are, if you like, external

independent people. So for me, it is like we just need to open that up so that we can see it. I do not doubt the integrity of all the people that work at the Disability Services Commission. I do not even doubt the integrity of the people who work in the schools that we talk about. But I think that certainly there are people who carry a level of prejudice that they are probably not aware of. I think there are people who know how to bypass the CAP process. One of the other ways that you can actually get into accommodation services, I guess, would be that you would have a crisis and that crisis led to you withdrawing any support that you were giving. So I understand that the Disability Services Commission accommodation support directorate are the people who have to manage those people who perhaps have had such a severe reaction to something that is going on in their life that their behaviour has become so out of control. An emergency has been created. People can access the Disability Services Commission accommodation support directorate that way. I do not know if there is any advantage to be gained by going that way in relation to receiving long-term funding, for example. I just do not know because those policies—and the staff must work to a set of policies and procedure, but they are not publicly available policy and procedure, so again, it is very difficult to challenge on the basis of policy and procedure if you do not know what it is.

Mr C.D. HATTON: So you respect the integrity of the people who work there, which is great, but you somewhat may not have faith in the way it is operating, through lack of transparency?

Mr Jefferson: I think that is right. All I am saying is that I think there is good reason to doubt that the processes are as they should be, because if they were, it would be a very simple thing to make those policies and procedures public. Why would you not do that? The commission have got a very comprehensive, very accessible website, and I could not imagine what benefit there would be in keeping that information to yourself. Yes, advocacy organisations would use it to hold people to account, as would some parents, I am sure, but I do not think that is a reason not to have that information available.

The CHAIR: There are some changes mooted, as I understand it, to the Disability Services Commission. I wonder if you know what they are or whether you have any views on the proposals?

Mr Jefferson: It would be fair to say that there are many, many changes taking place at the commission at the moment. Did you have a particular area?

The CHAIR: I gather that there is going to be a number of staff reductions there and then a lot of the work is going to be farmed out, I think, to private agencies.

[11.20 am]

Mr Jefferson: Okay. It would be fair to say that is not the language I use in relation to this. I hope I have not bought into anybody else's kind of language. But there was a recent announcement that the accommodation support directorate, which is the service and housing provision arm of the Disability Services Commission, were going to transition up to 60 per cent of the people that they currently provide services to, to the non-government sector is how it is described. I was led to believe that there would not need to be any redundancies, on the basis that the Disability Services Commission accommodation support directorate turn over 125 staff on a kind of—I am trying to remember the term I am looking for.

The CHAIR: Attrition.

Mr Jefferson: Attrition. Thank you.

The CHAIR: Annually—125 staff annually?

Mr Jefferson: Yes.

The CHAIR: Goodness me. It shows it is a stressful job.

Mr Jefferson: I am pretty sure, and again I need to be careful here—I have no great memory for statistics—but I understand they have over 1 000 staff in the accommodation support directorate, but then with 500 clients, I imagine that would be the case.

The CHAIR: We have got Dr Chalmers coming in, but I just really wanted to know from a consumer's perspective whether that is going to have any impact.

Mr Jefferson: I think it is going to have a huge impact. I have been asking for two years, is there a conversation taking place about people within the Disability Services Commission getting the opportunity to have a meaningful conversation about getting out, because typically they provide group homes and, as I previously indicated, I do not believe that is a particularly good model? I do not think it achieves good outcomes for people with disabilities, although I recognise that some people like it and want to stay there. So I am really delighted that conversation is going to take place and 300 people get the opportunity to say what it is, even just to start thinking about what it is, that they might like. I do know that this has triggered alarm in some parents who fought for years to get their sons or daughters into some kind of secure—not with locks and keys but some kind of security in their accommodation support. So they are terrified that what is going to happen is that the people are going to end up in the non-government sector; they will have new a provider; the provider is not going to be able to cope with their son's or daughter's special circumstances, because they are not as well trained as the Disability Services Commission staff are; and they will lose their home and their support. There are kind of two sides to this: one is that there is a celebration. People are going to have this conversation and might go into something better, something more appropriate, something that might lead to a better life. And then we have got a group of people who probably are unsettling their children as a result of being unsettled by this themselves. What I am pleased about is that the Disability Services Commission, at this very early point, have invited a group of five people who are independent to oversee aspects of this and that we are one of the organisations that have been invited to the table. So we take some comfort from that because if we have got things to say, we will say it, and the other people who are part of the group, I am confident, are independent, too.

The CHAIR: This conversation is about the type of accommodation as much as it is about who manages it. Is that my understanding? Is there a terms-of-reference group or anything?

Mr Jefferson: What we have been told and what we have been told publicly—just because there is some confidentiality that relates to my involvement in that independent group—but what we have been told at the disability coalition was that there will be one-to-one person conversations that will include all of the important people in their lives, that people will be invited to have a conversation about whether they want to stay where they are, and if they want to stay where they are, do they want to stay with the people that they currently live with, because if they do and all seven people in a seven-person group home want that, then that is going to be just a transactional exercise, so another service provider will fly in and effectively pick up the same support plans. There will just be different staff in that are doing it. There may well be some negotiation about whether some of the Disability Services Commission staff can stay in for a while and help to facilitate that. At its best, having been part of deinstitutionalisation programs in Scotland, I could see how that could work. What I would say is I would be so disappointed that 300 people have the opportunity to have an individual conversation and at the end of it all, they all decided they wanted to stay in the same house with the same people and were just quite happy for the staff to change. It would just be impossible to believe that that might happen. And it would be fair to say that I have some information about processes that are taking place prior to the start in January that I am quite unhappy about, but it would be fair to say that those matters will be taken forward to the Disability Services Commission robustly with regards to ensuring that a fair process is taking place. There will certainly be conversations taken about how can this be independently monitored; how can we be sure that people are asked after the conversation whether they took part in a consultation, a negotiation or a fait accompli.

The CHAIR: Just my final question, and someone else might have some more: if you were Ron Chalmers for a day, what would be the one thing that you would do; what would be top of your list to do?

Mr Jefferson: Look, for the Disability Services Commission and the work that the Disability Services Commission do as part of the government, there is no quick fix overnight. I mean, it is about turning an oil tanker. But what I would encourage anybody sitting in the director general's position to do is actually not just to take the advice of the people who sit in your executive circle and your middle management team but actually to spend some time, and I know to be fair to Ron he does, but I think there needs to be a much more concentrated consultation process with people at the coal face, and I do not mean the chief execs of disability service providers. We need to have support workers having the opportunity to get together to talk honestly about what goes on in their space and about the things they would like to change if they had a day in their chief exec's position. There needs to be an investment in building the capacity for people with a disability to take part in discussions and consultations in a way that they can cope with the power imbalance between the professional, "we know best" classes and the guys who are on the receiving end of policy they did not develop but was developed in their name with inadequate consultation and with, inevitably, an inadequate understanding of what it is like to be living at the coal face with a disability, with inadequate support, having no chance of accessing an affordable house, with having no knowledge of when support might become available, unless you are going to wait for the rollout of the NDIS, which may not even be in Western Australia in two-and-a-half years' time.

The CHAIR: Thank you very much. You are the first witness in this inquiry, so it may well be that when we get some more information we might have to clarify some of the issues you have raised, but we are certainly very grateful for your frankness, and I think it was a good wide-ranging discussion that we have had today. A transcript of the 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 is deemed to be correct. New material cannot be added through 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. Thank you for your time today.

Hearing concluded at 11.29 am
