

**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, 19 MARCH 2014**

**SESSION TWO**

**Members**

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

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**Hearing commenced at 10.22 am****Ms SUE HARRIS****Concerned individual, examined:**

**The CHAIR:** On behalf of the Community Development and Justice Standing Committee I would like to thank you for your interest and your 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. You have been provided with a copy of the committee's specific terms of reference.

I am Margaret Quirk; on my left is the deputy chair, Ian Britza, member for Morley; on his left is Chris Hatton, member for Balcatta; and on his left is Mr Mick Murray, member for Collie–Preston; and on my right is Dr Tony Buti, member for Armadale.

The committee is a committee of the Legislative Assembly of the Parliament of Western Australia and 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 a 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 documents during your evidence it would assist Hansard if you could provide the full title for the record.

Before we proceed to the questions that we have here today, I need to ask you a series of questions. Have you completed the "Details of Witness" form?

**Ms Harris:** Yes.

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

**Ms Harris:** Yes.

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

**Ms Harris:** Yes.

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

**Ms Harris:** No.

**The CHAIR:** Would you please state your full name and the capacity in which you appear before the committee today?

**Ms Harris:** I am a concerned citizen now, but in the past I have worked in a professional capacity as a social worker within the commission and as the CEO of the Developmental Disability Council.

**The CHAIR:** Thank you very much, for your excellent submission to the inquiry. Together with the information that you provide today, your submission will form part of the evidence to this inquiry and may be made public. Are there any amendments you would like to make to your submission?

**Ms Harris:** No, I have not specifically identified amendments, but there is heaps more I would like to say.

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**The CHAIR:** We have a series of questions to ask you but, before we do that, do you wish to provide the committee with any additional information or make an opening statement to the hearing?

**Ms Harris:** Yes, I would, thank you. I guess that my submission clearly outlines that I have very serious concerns, and always have had, with CAP. I think that it has three key fatal flaws. The first is that it just does too much damage to people; it is negative, humiliating and degrading. The second is that, primarily through a lack of transparency, it puts the system and not the person at the centre of the process, leaving people powerless and at the mercy of the system. And the third is that it does not provide useful data—the sort of data that is essential for planning—rather it provides broad, general data that seems more designed to shine a light on the number of people being helped. I think DSC has been seduced by CAP—it looks good; it sounds good; it looks sophisticated; it is clean and tidy; it uses fancy rating scales and it does the job; it produces a clear list of who to fund and who not to fund. I worked for the commission and with the commission for nearly 40 years. I know it is full of extremely committed people, lots of noble principles and it does a lot of very good work, but I think they have got it wrong when it comes to CAP.

**The CHAIR:** We actually have the chair of the panel in shortly; what is the one question you would ask her in terms of the process?

**Ms Harris:** I would like to know what she thinks of it.

**The CHAIR:** You said in your submission that there should be a waiting list. Dr Ron Chalmers has rejected that, but it certainly is something that appeals to me—the idea of people knowing that they might not get it this year, but that three years off they stand a good chance. That must be very important for people's optimism and hope, and their capacity to carry on.

**Ms Harris:** I think that one of the criticisms commonly made about a waiting list is that if someone falls into crisis, they clearly have to be parachuted up. I think that people in real crisis, like 90-year-olds or people who are facing incapacitating illness, or people who, if they do not get services, will suffer irreversible permanent damage, should just be funded. I think there is nothing justifiable in putting those people through a process whereby they wait several months. One example of this: we were running a conference in Fremantle and a lady who was having chemotherapy for the Xth time and had very limited time to live, said to us “What am I going to do?” She had an adult son with a severe disability, who simply could not look after himself and her husband was not able to look after him. “What am I going to do?” she said. We spied the head of DSC at the conference, and said to her, “There is the person in charge, go and speak to her and make your case.” When she went up, which she did, which was very brave for someone to do, especially in her condition, she was told, by her first name, “Hello, yes, I know your situation, all the best with the panel, it is meeting in two weeks.” To me, that just highlights the inhumanity of this process; you just cannot do that. With anybody in that sort of crisis, just fund them. If you run out of money, you run out of money; plead your case. But there is nothing justifiable in making those people wait to go through a formal process.

**Dr A.D. BUTI:** We have also heard with regard to the CAP scheme that it is not transparent or accountable. When we put feedback to Dr Chalmers, he said that there is sufficient feedback; there is a two-page letter, et cetera—I think that is what he said. He said that, in fact, feedback is better now. That is not what we are hearing. Can you just elaborate a little bit on the transparency issue and also feedback, accountability and so forth?

**Ms Harris:** Well, it almost totally lacks transparency. People do not know who is making the decision, on what basis and they have no opportunity to appeal. And at the end of the process, they are in a void and have to start all over again.

**Dr A.D. BUTI:** And feedback?

[10.30 am]

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**Ms Harris:** Feedback is by a formal letter. I do not think life-devastating news should be delivered in a formal rote letter. And the data that is provided is well-nigh useless; it does not tell us who is getting what and it does not tell us who is not getting what, you cannot track what is happening to subgroups and you cannot track what is happening to people with specific needs. In my case, coming from a background with the commission and DDC; what is happening to people with intellectual disability? What is happening to the people with the highest support needs? What is happening to parents as they near the end of their lives? It does not help us to know that X number of people are getting funding; who are they and what are they getting?

**The CHAIR:** Dr Chalmers also said that those who were missing out were getting other support packages. We have put that to a number of people in the industry and they looked somewhat perplexed. What is your experience in that regard?

**Ms Harris:** I personally find the statement quite meaningless. An analogy I can think of is if someone is starving and you give them a crumb a day; it makes no difference. For example, if you have got elderly parents facing the end of their life and they just cannot do it any more—we are talking 70, 80 and 90-year-olds—and they are offered three hours' respite a week. It is just irrelevant. It is meaningless. It sounds good, but it does not feel good on the other side.

**The CHAIR:** We have also heard evidence that some years ago—certainly when I was involved—there was a lot more feedback about who got it and what percentage missed out. It seems that some of that information is not now getting out. If you get a rejection letter and you can say that there were 800 applications for X number of places, you then realise your probability of being accepted is quite low. But they are not even getting that level of information, I understand, now. Are you aware of the reason for that?

**Ms Harris:** I suppose if you drill into it, what I have often thought is I am not privy to what goes on between ministers and departments, what pressures are put on who by whom to do what. What I do know from the other side of the fence is that this lack of information almost looks like a culture of denial and secrecy, and the victims are people with disability and their families. The way I see it, the commission has been set up exactly for people with disabilities and their families, so what is happening should not be happening.

**The CHAIR:** In your submission, you say that the CAP process is based on a group of experts periodically ranking the crises and degree of need. You put experts in quotation marks and I wondered if that was significant.

**Ms Harris:** I just assume they are experts; I do not know. I suppose the other thing is, as a social worker, I find it almost unfathomable that people can be ranking people's crises on the basis of paperwork. Looking at my own life—I am sure we could look at our own lives—how could somebody have ranked how near or not we were to crisis on the basis of what we put down on paper two months earlier? Crises just happen, and they surprise the person themselves even, as much as anybody else. The notion that they are accurately ranking people and fairly distributing money on the basis that unknown people are ranking you from a set of paperwork, as a social worker, is just silly.

**Dr A.D. BUTI:** During your time with DDC, or even after, how prevalent was the situation that people have just given up?

**Ms Harris:** Very prevalent.

**Dr A.D. BUTI:** Could you estimate the percentage?

**Ms Harris:** It is very hard to do that. We were in a position in which people would come to us with their stories, because we were safe. We were not the system; there were no consequences. If anything, we were more likely to help them than hinder them, so we heard a lot of those stories. I do not know, but we clearly did not hear as much from people who were getting what they needed, although I know there are not that many of them. I would say there are enough to be concerned—

definitely enough to skew the data significantly, and definitely enough to be very concerned with that.

**Mr C.D. HATTON:** With your experience and background, which is obviously quite deep, do you have any stories from other states of Australia that do it better or have models that are better?

**Ms Harris:** The whole situation is skewed by a massive shortfall of funding, and that is common across all states. I know in Victoria they do have a waitlist and it is long—very long, as ours probably would be if we were not —

**Mr C.D. HATTON:** Do you think that a waitlist is a reasonable idea?

**Ms Harris:** I personally, and from what I have been told by families, would find it helpful to have some sort of a waitlist—or as someone put it to me the other day perhaps a better title is a register of need. I think that would be helpful—more helpful than not. But I cannot point to other states and say it is being done better there, because I am not familiar enough with the details of how their system works and I have not spoken to enough families there to know how it feels on the receiving end.

**Mr C.D. HATTON:** Also, with the level of funding, do you have any understanding of funding in the other states compared with our state?

**Ms Harris:** My colleague, Deidre, behind me has done a detailed analysis of that over the years. We basically fall in the middle of them. Victoria is up the top; we are somewhere in the middle—or we were at that time, even with our increases. I must say that governments of both political parties in WA have responded positively in putting in ongoing increases in funding over the years. They have been very significant and very large compared with other sectors. But given where we got to in terms of the backlog and given that from dealing with intellectual disability the system now also deals with all people with disability, the funding has been markedly too little.

**The CHAIR:** In terms of meeting demand, one of the issues that obviously comes up is that we have an ageing population, so carers that previously, if you like, did not rely on the system, are now getting to an age and maybe the state of their health is such that they have now got to come into the system.

**Ms Harris:** Yes.

**The CHAIR:** We would expect, just from demographics, that there would be a significant increase in demand.

**Ms Harris:** Yes.

**The CHAIR:** That is your experience. Are there people who are outside the system that need to come in at some stage?

**Ms Harris:** Definitely, yes.

**Mr M.P. MURRAY:** On the people who look at the submissions: I assume not, but is there any weighting given to the time factor in their criteria, or do they just have to keep going back in each time with no weighting—for example, whether they have been waiting six years or two years?

**Ms Harris:** I do not know. That will be a question for Sherry.

**The CHAIR:** We have heard some evidence that there seems to be some disparity in the CAP process between the waiting time that people with physical disabilities have compared with people with intellectual disabilities. Do you have any knowledge or understanding of that or any anecdotal evidence?

**Ms Harris:** No. The main thing I say to that is that through my role at DDC we were always after better data. That is the sort of data that we believe should be there, and people should know how the

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different subgroups in disability are faring, not so that they can war with each other, just so that we have a picture of what is going on.

[10.40 am]

**The CHAIR:** Another thing I was going to ask relates to the fact we have heard there is some reluctance to talk to us because it may be seen as prejudicing people's own prospects within the process. Is that something you have had any experience of or are aware of?

**Ms Harris:** I have not, because I had left DDC before this process was initiated. But I certainly know that people are very concerned not to do anything that might jeopardise their situation. Also, given the total lack of transparency around everything to do with this process, people do not know on what basis decisions are being made. So I would imagine that some people would be wary.

**Mr I.M. BRITZA:** You are very frank. But those applying would not be so frank, because they would feel it would jeopardise their application.

**Ms Harris:** I would expect so, yes.

**Dr A.D. BUTI:** In your submission, you talk about the culture of secrecy. Why do you think there is a culture of secrecy?

**Ms Harris:** As I said before, I am not privy to what goes on between ministers and the bureaucracy. I do not know whether politicians do not want to know because they do not want to be in a position of having to put in more money. I do not know whether the commission is not telling them because it does not want to be seen not to be managing its budget properly and it does not want its failings to be highlighted. I do not know what goes on between those two arms of the system.

**Dr A.D. BUTI:** We still are a small town—perhaps not so small any more—but, in your assessment, do some players play a bit more than other players? Do some agencies play a bit more than other agencies and so forth?

**Ms Harris:** Quite possibly.

**The CHAIR:** You have also talked about lack of choice in living arrangements. Can you expand on that a bit for us?

**Ms Harris:** If you choose to live with other people, as my children did when they left home, and as I did when I left home—and for some people with intellectual disability, their families may feel it is better that they are with other people—then you need to live with people who you want to live with and people who are compatible. If you have to rely on other people who have also got funding, that is a very small pool. The number of people who get funding is only a tiny number. Also, the chances that you will have a compatible disability, will want to live in the same area and will like each other are pretty well impossible. So the system as it is operates to rule out group living options, and I do not think that is a good thing. One of the advantages of having a register of need, to my way of thinking, is that we would have a much bigger pool from which to find compatible people. And while you are parachuting people up the waitlist, I think if this was clearly explained and transparent, people would be more than prepared to accept that.

**The CHAIR:** Thank you very much, Sue. We were just talking before you came in about the adopt a politician scheme, and how terrific that is in increasing people's awareness. So now that you are retired and just a private citizen, your legacy lives on, I think.

**Ms Harris:** That is good.

**The CHAIR:** Thank you for giving 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

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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.

We should be finishing this inquiry in May. It is a reasonably short, sharp one, but our idea is to get a bit of a benchmark about how things are going so that as we move forward either with the NDIS or My Way or whatever, we have got some basis for comparison down the track. So do not be disappointed if this looks a bit flimsy. It is more a question of us getting a snapshot as of 2014 to see where we are at. Also, the NDIS is still some way off, as you said, and we will have to see what happens in the meantime.

**Hearing concluded at 10.45 am**