

STANDING COMMITTEE ON PUBLIC ADMINISTRATION

INQUIRY INTO THE PATIENT ASSISTED TRAVEL SCHEME

**TRANSCRIPT OF EVIDENCE
TAKEN AT KALGOORLIE
TUESDAY, 26 AUGUST 2014**

SESSION FOUR

Members

Hon Liz Behjat (Chairman)
Hon Darren West (Deputy Chairman)
Hon Nigel Hallett
Hon Jacqui Boydell
Hon Amber-Jade Sanderson

Hearing commenced at 12.29 pm**Ms VANESSA HOOK****Parent of patient under 18, sworn and examined:****The CHAIRMAN:** Vanessa, hi. How are you?**Ms Hook:** I warn you, I am a nervous public speaker!**The CHAIRMAN:** Please do not be! I think you might have picked up on the vibe that we are all pretty approachable and we are not here to judge people or to do anything like that, but we do need to go through some formalities with you. Would you take an oath or an affirmation for us, please.

[Witness took the oath.]

The CHAIRMAN: You will have signed a document entitled “Information for Witnesses”. Were you able to read and understand that document before you signed it?**Ms Hook:** I was, yes.**The CHAIRMAN:** Terrific. The proceedings are being recorded by Hansard and a transcript of your evidence is going to be provided to you. To assist the committee and Hansard, please quote the full title of any document you may refer to during the course of the hearing for the record. Please be aware of the microphone and try to speak into it. I remind you that your transcript will become a matter for the public record. As we said with John before, if there is some reason that you would like us to hear your evidence confidentially and that you do not want to share that in public, please let us know that. We will take that consideration on board, and if we grant that request, we will clear the room of the public and media who may be here, to exclude them from the hearing. So, please, at any stage, if that is what you feel you would like to have happen, let us know. Please note that until such time as the transcript of your public evidence is finalised, it should not be made public. I advise you that publication or disclosure of the uncorrected transcript of evidence may constitute a contempt of Parliament and may mean that the material published or disclosed is not subject to parliamentary privilege.

That is the formal part. You have heard all our names. Please feel relaxed, feel comfortable. Do you want a glass of water?

Ms Hook: No, I am fine, thanks.**The CHAIRMAN:** In your own words, tell us your PATS story.**Ms Hook:** I guess I am here today, first, to tell you my son’s situation and also mostly because I would like for the committee to consider extenuating circumstances. Currently, we do not qualify for the PAT scheme. My son, Rohan, is profoundly deaf and has been deaf from birth. He has a cochlear implant and has recently been down for surgery for a second cochlear implant.**The CHAIRMAN:** With Marcus Atlas?**Ms Hook:** Actually, yes.**The CHAIRMAN:** Excellent.**Ms Hook:** He is a miracle—you will make me cry—worker!**The CHAIRMAN:** He is absolutely gorgeous!**Ms Hook:** He is, yes! The PAT scheme will actually cover travel for surgery; okay. So, devices get implanted, but from there on in we are not covered because this falls under the umbrella of

audiological services under allied health. Our situation is that I travel to get Rohan there for the surgery, but then you have what is referred to as “switch on”, where all the electrodes are activated so that they have, hopefully, access to sound. These electrodes need fine-tuning over quite a large period of time. Each patient is different as to how many appointments they need and how frequently they need them. It all depends on the progress of the child, none of which is covered. Recently we have gone down for surgery, and we had to relocate for three months away from our home in Coolgardie. It is a little bit emotional, because we spent quite a bit of time away from dad, and dad spent that time on his own, working and trying to support the family as well. The nature of Rohan’s condition is that I homeschool him, and I homeschool his brother also, so when we have a situation like this, what it has meant is that we had to relocate for three months. It has had an emotional impact on my children and myself and my husband. It has impacted on their education also. I would like for these sorts of conditions to be considered under extenuating circumstances. In the past, when Rohan was first implanted with his left ear when he was quite young, we did apply under extenuating circumstances to be covered when we were in the Pilbara, and they did fly us down. I have tried to go through that process again here in Kalgoorlie, and I have found admin staff quite unhelpful within the PATS office.

The CHAIRMAN: So, you have actually applied for exceptional circumstances and you have been rejected?

Ms Hook: I have tried to. The process that I have gone through is I have rung the department or I have rung the office here. Basically, we are not covered. I asked, “Well, who do I speak to?” I was away at the time trying to see whether we could further coverage past surgery for these audiological visits. The lady that I spoke with would not give me a name or a number of anybody further that I could put this to. She said, “The best thing that you can do is email me.” I did not have the option to email at the time; I did not have internet and because of appointments it was made quite difficult. And I was saying to her, “Look, I don’t have this option. It is too difficult for me at the moment.” She goes, “Well this will be the easiest and the best way to do it”—absolutely flat-out refused to give me any further information on the best way. So I ended up ringing Esperance and one of the ladies in Esperance was the lady who gave me the information that I needed. She told me who the regional coordinators were and email addresses and I flipped off emails to the people with regards to our situation.

The CHAIRMAN: Just let me stop you there. How long ago was that phone call to Kalgoorlie where they said, “Email us and we’ll talk about it?”

Ms Hook: Say three months ago.

The CHAIRMAN: Three months ago?

Ms Hook: Yes, directly after surgery.

The CHAIRMAN: And when was Marcus’s surgery?

Ms Hook: Sorry, Rohan’s surgery.

The CHAIRMAN: Rohan’s surgery, I am sorry.

Ms Hook: It was 21 May. So, Esperance office actually gave me the relevant contact details, so I fired off emails. I actually made a phone call and then emails. My emails have gone to date unaddressed, and it has not gone any further. I suppose what I would like —

The CHAIRMAN: They have gone unanswered.

Ms Hook: They have gone unanswered, I should say. What I would like to highlight is that this is the fight that when people are passionate about something, they are prepared to fight but at some point they are going to give up on that fight, you know, whether they are entitled or not.

The CHAIRMAN: So Rohan has his first cochlear implant when you were in Karratha —

Ms Hook: Correct.

The CHAIRMAN: Was it Karratha did you say?

Ms Hook: Actually no, we were in the south west, but we were flying down from Karratha; we had relocated.

The CHAIRMAN: So he has the cochlear implant first and then he does get follow-up visits at that point covered under the PAT scheme for the first implant?

Ms Hook: No, he does not. The surgery is covered.

The CHAIRMAN: :The surgery was covered?

Ms Hook: Nothing else is covered, but it is like, I guess, having a pacemaker put in; there is no point in having the device if you are not covered for switch on.

The CHAIRMAN: So he now has his second?

Ms Hook: He has now recently had his second, and it meant that we needed twice weekly appointments at Princess Margaret Hospital. He has also had complications with something called overstimulation, which needs to be addressed immediately.

The CHAIRMAN: Yes, absolutely!

Ms Hook: So, being six hours away you cannot just travel down twice a week to have the necessary treatment. Then if he does suffer something like this overstimulation that he has had—and he is quite the anomaly—it has to be dealt with straightaway. So we actually relocated to the south west for three months where we have got almost an uninhabitable renovation project down there; and we were travelling from there for three months from that point in order to be that bit closer to, because we could not afford inner-city accommodation and be close to Princess Margaret Hospital for Children and we do not have the family supports either. So, that was the only option that we had. Had we not done that, we would not have been able to pursue the dream for Rohan to be bilaterally implanted and hopefully overcome the disability. His choice to have this done has been on the back of 12 months of hardship with discrimination in the community, you know. So, he has had a very positive deaf identity and he has had quite a challenging 12 months. So, he himself has questioned his own identity and then wanted to pursue this to overcome the disability. And what we find typically —

The CHAIRMAN: How old is Rohan?

Ms Hook: He is 12, and quite often, yes, there are these challenges, particularly under audiological. It seems to be that condition that you fall within loopholes where you are not covered for quite a few things where other conditions are.

The CHAIRMAN: I am assuming Marcus is seeing him via the Ear Science Institute.

Ms Hook: We are actually under PMH at the moment. Marcus did the first surgery but it has been PMH and a different ENT doctor, Dr Rodrigues, who has done the second implant.

The CHAIRMAN: At any stage has he provided you with some support documentation to say that this is absolutely vital?

Ms Hook: This is the process I am going through at the moment. I am going to request that information from Dr Rodrigues to see whether that would in actual fact help this situation.

The CHAIRMAN: Have you ever spoken to somebody who is the administrator at the Kalgoorlie Hospital with regard to the exceptional circumstances?

Ms Hook: No, I have not.

The CHAIRMAN: Geraldine Ennis, you have never had a conversation with her at the hospital?

Ms Hook: No. I have only dealt with the PATS department themselves. I did not realise that I could speak with the hospital themselves.

Hon AMBER-JADE SANDERSON: This may not be a question for you but I am wondering if you know the answer. Are there other conditions where surgery is required and then follow up when those follow-up consultations are covered, like a pacemaker for example, that you are aware of?

Ms Hook: I know of a family in Kalgoorlie whose daughter has a brain condition, and I was hoping that she would come today and tell her story. I am not overly familiar with it, but I know she has had dreadful trouble with the PATS department where her daughter cannot sit for long periods of time. So, say, train travel is not appropriate for her and therefore would require to fly, which is only like a 45-minute flight to and from Kalgoorlie. But I think it's the actual administration team that determines whether that is possible or not, but do not quote me on that.

[12.40 pm]

Hon DARREN WEST: Had you qualified for PATS, how would things have been different for you?

Ms Hook: We could have travelled down on the train and the time away from home would have been minimalised. We would have had contact with dad. It would not have been as disruptive to education. My kids have been quite upset being away from their dad for that length of time. You know, in the past they have only been away for two weeks, I think, at most. It has been really difficult to the point where we flew dad down to spend three days because we felt that emotionally it was just important. I mean, you know the effect that FIFO has on families.

Hon DARREN WEST: Sure. So you would have had to catch a train from Coolgardie down and back.

Ms Hook: Down to Perth and back, and it would be a three-day turnaround. And, you know, it is still a long time out of a week but you are still having contact, you are still able to get back to routine. And we do not have a great network to be able to draw upon, so things like, "Can you feed the cat for us? Can you feed the chooks for us?" You know, there are those things that still have to be covered in day-to-day life, and having to repeatedly ask people to do that for you, whilst they do it, you know, they have their own families.

Hon DARREN WEST: Yes, we have chooks too!

Ms Hook: So, heading down to Perth when you do go down and you do want to be within, I guess, public transport access to the services—like John was saying earlier—accommodation costs are huge. For us having to be down at appointments twice a week for four weeks, and then appointments start moving apart slightly, accommodation costs are a killer; they really are. Then when you are travelling with two children, and Rohan's younger brother has to come with me as well and he is a bit over it, you know. He is following behind his brother and watching him live this hearing-impaired life, and then you have somebody who falls within the shadows. So, yes, that is how it has impacted.

The CHAIRMAN: Vanessa, thank you for coming today.

Ms Hook: Thanks for listening.

The CHAIRMAN: Your story is an interesting one. Can Rohan hear me now?

Ms Hook: To a degree. He has got a device in his hand so —

The CHAIRMAN: Like everything!

Ms Hook: I do not normally condone this but this was too important to have —

The CHAIRMAN: No, no. You can sell this to your home-school children as an outing today but it is not going to qualify as a fun thing to do I can assure you of that.

Hon AMBER-JADE SANDERSON: It is a visit to Parliament.

The CHAIRMAN: Yes, their only visit to Parliament. Good luck with it, and hopefully you will get a better outcome. Thank you so much for coming.

Ladies and gentlemen, that concludes our hearings for this session and we are going back into session at 1.15 pm with our next witnesses this afternoon. So you are very welcome to come back in but we need to clear the room now so that we can talk about some things and you are welcome to come back this afternoon, but thank you very much for your attendance here today.

Hearing concluded at 12.42 pm
