

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 6 March 2017

Members

Ms Maree Edwards — Chair

Mr Paul Edbrooke

Ms Cindy McLeish — Deputy Chair

Mr Bernie Finn

Ms Chris Couzens

Witness

Mr Shane Pendergast (*via audio link*).

The CHAIR — I welcome to today's public hearing Mr Shane Pendergast. Thank you for attending today. All evidence at this hearing taken by the committee is protected by parliamentary privilege, as provided by the Constitution Act 1975, and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today, and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary. Shane, the committee would invite you now to make a brief statement, and I will hand over to you.

Mr PENDERGAST — Thank you. An introduction to what we are talking about — we are talking about Mansfield and camps in general and the services out there. Is that what I am talking about?

The CHAIR — Yes, I believe that is correct. You live in Bairnsdale?

Mr PENDERGAST — We live in Bairnsdale, and we have obviously used Mansfield quite a bit. Our young bloke attended Mansfield and has also attended the camps which we found. Mansfield was great. He spent eight weeks over there. Obviously he was working on his life skills and working on his behaviour. They were fantastic. Certainly it was a life-changing experience for him and also us.

The CHAIR — Can I ask how old Connor is?

Mr PENDERGAST — He is 13 now. He was seven when he attended that first lot of camps and obviously the things at Mansfield, which are very hard to get into. We were lucky enough to get him into them. He spent nearly eight weeks doing that. They worked intensively with him, just basically getting his life skills sorted out. We have attended a few camps since. He has got an older brother, so it gives us an opportunity to spend a bit of time with him. We all go to the camp, and Brady goes off doing different things while Connor is obviously with a carer. We find that very helpful as well.

The CHAIR — How old was Connor when he was diagnosed with ASD?

Mr PENDERGAST — He was probably around about four or five. Obviously we know early intervention is a great thing and whatever, but the trouble down here is that unfortunately you do not have the services to provide it. He also has epilepsy, so when Connor was at camp in Mansfield we actually had to pay for a registered nurse to come every morning and monitor him while he was having seizures, because he always has seizures when he first wakes up. So we paid for that. That cost about \$5000 to do that.

The CHAIR — Do many of the children who attend the camp also have other medical staff or other assistance provided for them?

Mr PENDERGAST — Not really, no. We obviously wanted it for Connor. It was something that the camp, when he was at Mansfield, did not provide. It is obviously an extra fee that we had to pay, so we were quite happy to pay that. He did visit hospital a couple of times. He spent a couple of nights in the hospital over there. They were concerned about his seizures. But it was just something that we wanted to safeguard against, and they were quite happy. We went over there a couple of weeks before he was ready to attend it, and we did some training with them. They were great there; there is no doubt about that. It was just that the distance was a bit of a problem. There is nothing unfortunately around in East Gippsland like it.

The CHAIR — No, that is correct. Did you stay in Mansfield while he was doing that eight-week therapy?

Mr PENDERGAST — We did, yes. We were only allowed to see him three times in the eight weeks. So the first night we stayed and went back to visit him. Then after that we were only allowed to see him another two more times in the eight weeks. That was a little bit tough, but he got used to it. I think the second time we visited he was quite happy doing different things. It was certainly a life-changing thing for him.

The CHAIR — Can you explain how it was life changing for him?

Mr PENDERGAST — I suppose the thing that they worked hard for was toilet-training him and getting him to eat and obviously social skills and life skills. They worked quite extensively with him. He went there un-toilet-trained and basically came out of there 90 per cent trained. Obviously kids with autism are very particular in what they eat, and they worked hard with him there. They worked hard with him on the social

aspect of taking that into the public. It was great what they did with him. They extensively put a lot of time into him. Fortunately for us it all worked well.

Ms McLEISH — Thank you for joining us, Shane. I am interested in the referral source. How did you find out about the Mansfield service?

Mr PENDERGAST — Because my young bloke attends a special school, Mansfield at the time had travelling teachers that would go around and just visit people, especially in country areas. That is how we found it — through the specialist school. We contacted them and worked with them to get Connor in there. At one stage I think they were telling us it was up to a four or five-year waiting list to get into the school. That probably gives you an idea of how popular it is. Through their travelling teacher and also through the specialist school is how we first found out about them.

Ms McLEISH — What was the wait for you to get in?

Mr PENDERGAST — We were not too bad. We probably had to wait 15 months to 2 years, I suppose, to get in there.

Ms McLEISH — And you got in when he was seven?

Mr PENDERGAST — Yes, and he has just had brain surgery at the moment for his epilepsy, so we actually would not mind getting him in once more. But they are telling us at the moment that there is a huge waiting list, so we are not sure.

Ms McLEISH — Can I be clear: he did the eight-week residential program first and then you have done the camps since?

Mr PENDERGAST — Yes, that is correct.

Ms McLEISH — How many camps did you say you have done?

Mr PENDERGAST — We have probably done four. We have not done one for a while. Obviously Connor has kept away from the school a bit, but we have done four, mainly for Brady, our youngest son. My wife went to one there. Probably the last time would have been two years ago. She attended, and obviously it was good for his older brother to do different things while Connor was being looked after.

Ms McLEISH — What was the experience like for his brother?

Mr PENDERGAST — He loved it. He thought it was great. Brady had a buddy as well from the camp who took him off horseriding, abseiling, canoeing and rafting and everything, so he loved it. He actually looks forward to going on those camps.

Ms McLEISH — Just my final question around that: what was the interaction with you and Linda as the parents with the service? Did they help with different elements for you or provide any means of support?

Mr PENDERGAST — As in when we got there or in general? Linda and I do not receive any funding for Connor whatsoever.

Ms McLEISH — He attends a special school, though.

Mr PENDERGAST — He is in a special school, yes, but he is not at the moment; he has had brain surgery, so he is at home. We do find the funding very difficult.

The CHAIR — I am sorry, Shane, I am a little confused about the funding arrangements. If Connor is attending a special school, generally it is based on criteria around IQ and then eligibility for disability support funding through the education department. You do not get that for Connor?

Mr PENDERGAST — Nothing, no. I will give you an idea. We had a representative come out to our place. I will not claim where they were from. Probably because I and my wife have set ourselves up fairly well over the years and have got a nice house and a pool and what have you, she was more concerned about what we have

and commented to my wife that, 'You're obviously very well set up in a loving family. You don't need much support'.

The CHAIR — How long ago was that?

Mr PENDERGAST — That was 17, 18 months ago. We actually put a complaint in. The fact is it was not about money; it was about giving us time — my wife having time to go shopping and doing that sort of thing. Money is not an issue. But that was our concern. We have not for some time received anything for Connor — any support or funding.

The CHAIR — In addition to the epilepsy, does Connor have an intellectual disability?

Mr PENDERGAST — Yes, he is autistic and he has global developmental delay.

The CHAIR — Thanks.

Ms COUZENS — Hi Shane. How are you going?

Mr PENDERGAST — How are you doing?

Ms COUZENS — Good. Thanks for calling in today.

Mr PENDERGAST — That is all right.

Ms COUZENS — Have you or your wife been involved in any parent support or advocacy groups in your community?

Mr PENDERGAST — My wife works within the special school. We have got a good channel of friends that obviously work within the special school. They do help us out. But no, she has not. For a period probably 12 or 18 months ago she was involved in a smaller group, but no, she is not at the moment.

Ms COUZENS — Have you received any information about the NDIS?

Mr PENDERGAST — No, I have not. That is something we are interested in looking at. We were only made aware of that through Mansfield when they spoke to us some time ago. They actually rang us about this and said just be aware of the NDIS, because we do not receive anything for Connor. Nothing.

Ms COUZENS — What do you think the challenges are for people who are accessing services for children with ASD in your regional area?

Mr PENDERGAST — The amount of information that is required; the hoops you have got to jump through. That is one thing we certainly found. We were properly in the system with Mansfield back in 2007, and we got assistance from lakes community health with some support towards that. But every time you go back, you have got to jump through hoops for some reason; I do not know whether they think things change. As I said, our last experience with one of those service providers was not very good. It is not money we are after; it is just obviously having carers and being able to get someone to look after him to give my wife a bit of time off — —

Ms COUZENS — That respite care is something that you are trying to access.

Mr PENDERGAST — Yes. The last respite care they gave to us was a while ago, and they said, 'Unfortunately you have got to take him to Sale, drop him off at 8 o'clock in the morning and pick him back up at 8 o'clock the next morning'. I am wasting time driving an hour down the road for him to stay down there and then come back the next morning to pick him up again.

Ms COUZENS — What do you think will be the challenges for Connor as he moves into adulthood?

Mr PENDERGAST — What carer facilities are out there and available for him. We are doing a lot ourselves, obviously paying for stuff ourselves through different programs and getting people to work one-on-one with him. But what is the future for him? It is an unknown. I do not know whether the NDIS is going to be a good thing. I am not sure. We have people who look after him through the school. We pay

ourselves, but obviously they have to be trained and know about epilepsy and stuff like that. We have spoken to a couple of them, saying, 'You've got people who are trained, who are registered; why can't we use them?'. Of course you cannot do that.

Ms COUZENS — Thanks, Shane.

Mr PENDERGAST — No problem.

Mr FINN — G'day, Shane. Thanks for joining us today. I was going to ask that last question that Chris asked: what is the future? But you have covered that. I just wonder in an ideal world what the changes would be that you would like to see made to make your life easier or your wife's life easier and Connor's life easier.

Mr PENDERGAST — There are probably great services out there, but you just do not know where to go. It is a minefield about where you start and where you finish and the hoops you have got to jump through. As I said, we have had a bad experience with one of them and we have not been back since. But every time you go, which we have not for a while, to seek a grant or get assistance, you have just got to do so much to get anywhere, and that is the one thing that we have found just becomes too hard after a while. We are not chasing money; we just want the right carers for him to assist him — to take him out or take him to different places — but we have not been able to do that. Unfortunately we do it all ourselves, which puts a fair bit of strain on my wife. That is the problem moving forward.

Mr FINN — Shane, do you find there is a degree of scepticism amongst the bureaucracy as to your actual needs?

Mr PENDERGAST — Yes, very much so, and I do not think that will change. I really do not know what the answer is. Every kid's needs are different, and the trouble with my own kid is with his epilepsy and having the right people to deal with that as well. Socially he is not bad; we try to socialise him as much as we can. We would like different people to be able to help us with that as well, but being in the country unfortunately there are limited services for what you can do.

Mr FINN — Yes, I was going to ask just how limited are those services in the country. I have been to Gippsland a few times in the last 12 months, talking to people down that way about what is available and what is not available. How do you find the availability of services down your way?

Mr PENDERGAST — Terrible, mate. I only know of one — lakes community health. That is the only one I know of.

Mr FINN — That would be a priority for you obviously.

Mr PENDERGAST — I have only ever tracked things through getting to Mansfield or through the specialist school. That is the only way that we have managed to get Connor to Mansfield and camps and stuff like that obviously because of the travel et cetera and their going to the specialist school. Lakes community health is the only one I know of down here.

Mr FINN — Shane, I wish you well and thanks very much for the chat today.

Mr PENDERGAST — Thanks, mate. No worries. You are welcome.

The CHAIR — Shane, you mentioned the school options available down in your area. What will be the secondary school options that will be available to you for Connor?

Mr PENDERGAST — There will not be. There are not any.

The CHAIR — There is no secondary school in Bairnsdale?

Mr PENDERGAST — No. There is, but certainly for Connor, once he finishes at East Gippsland Specialist School, there is no other option except [inaudible].

The CHAIR — So he will have to go to the Bairnsdale public secondary school?

Mr PENDERGAST — Well, he will not be able to, because he will not be able to cope with it.

The CHAIR — Obviously he will be reassessed once he goes into that year 7 group, so do you think there might be an opportunity to perhaps get some support for Connor within the secondary school system once that assessment is done?

Mr PENDERGAST — I do not think he will be capable of being sent to secondary school. I cannot see that happening.

The CHAIR — What do you see as the outcome of all that? What do envisage will be the future?

Mr PENDERGAST — I envisage the next step up for him is probably [inaudible]. I would say that would be the next step up; that is the only service we have really got here.

The CHAIR — Okay. Cindy has another question, Shane.

Ms McLEISH — It is just a quick one. Shane, do you know many other families in a similar situation?

Mr PENDERGAST — Yes, I do. We had a lady out yesterday who has the same problem. Just got assessed by what they had and not what their needs were, and they do not receive anything at all as well.

Ms McLEISH — What about the people with children that have ASD? Do you know a lot of families down in eastern Gippsland where that is the case?

Mr PENDERGAST — I do. I am on the board of a specialist school, and we see it quite often.

Ms McLEISH — So you know them through there.

Mr PENDERGAST — Lots of kids with disabilities, as you know, do become expensive to look after.

Ms McLEISH — What about just the regular schools? Do you know if there are kids that are on the spectrum there?

Mr PENDERGAST — There are. We have quite a few across at the specialist school. My wife actually works at the specialist school and obviously goes to some of the other schools as an aide. Yes, there are quite a few on the spectrum; there is no doubt about that.

The CHAIR — Shane, on behalf of the committee, can I thank you very, very much for your time this morning. It has been very informative for us to hear about your concerns and Connor's concerns and also about some of the issues that you are facing. Would you like Connor's name redacted from the public record today?

Mr PENDERGAST — No, that is fine. I have one question to ask you guys: do you think the national disability thing is going to be a bonus for us or not?

The CHAIR — I am not sure about that, Shane. I think it is something that you probably need to speak to someone from the NDIA about, or alternatively your local member of Parliament might be able to help you with that. Because it is not due to roll out until 2019 in your area, you have some time to look into it and find out exactly where Connor will sit in terms of support. Can I make another suggestion around the clear lack of support for Connor, and that is that you perhaps approach the Minister for Education or email him to ask what might be available for Connor as he transitions into secondary school and even in terms of current funding. Thanks again, Shane. You also mentioned your other son's name.

Mr PENDERGAST — Brady.

The CHAIR — Are you okay for his name to appear on the public record?

Mr PENDERGAST — Yes, that is fine. No problem.

The CHAIR — Thanks very much, Shane. Much appreciated. We wish you and your family well.

Mr PENDERGAST — Thank you very much. Pleasure.

Witness withdrew.