TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Swan Hill — 14 February 2017

Members

Ms Maree Edwards — Chair	Mr Paul Edbrooke
Ms Cindy McLeish — Deputy Chair	Mr Bernie Finn
Ms Chris Couzens	

Witnesses

Mr Brenten Hogan and
Ms Janelle Hogan.

The CHAIR — Welcome today, Brenten and Janelle. Thank you so much for being here. 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. Brenten and Janelle, we have invited you today to present to us for around 15 minutes, so it is entirely up to you if you want to take all that time presenting or if you want us to ask questions, so over to you.

Mr HOGAN — Thank you for having us. Janelle and I have got four children. We have got a 16 and a 15-year-old, and then Cade, who is on the autism spectrum, who is 12 coming on 13, and then we have got Jye, who is 11.

We noticed Cade at an early age. Everything seemed to be fine at the start, and then probably around the age of two just a few little things were happening, such as banging his head — just a few things that just were not right. So we went to our local doctor, who passed us on to a paediatrician. I was at work, so Janelle took Cade to the paediatrician. We did not have the best experience. Janelle came home in tears, so I just said, 'Look, we'll book in for another appointment', because he believed that there was autism there, but he could not explain why.

Two weeks later the paediatrician had come back up from Bendigo. We visited him. He could not remember us, and when we went in he asked what the concern was. I just said, 'Look, we're here because we're a bit concerned about our young fella. We're just trying to work out what we're up to'. He just asked what our concern was, and we said that there could be autism. He asked what his name was. We told him it was Cade, so he said, 'Cade, Cade', and tried to get his attention. Cade would not turn around, because he was playing with a toy, and he turned to us and said, 'That's autism'. We said, 'But he could be shy', and he said, 'No, if he's not going to look at me, that's autism'. That was our first experience with this autism spectrum.

The CHAIR — And he was aged two?

Mr HOGAN — He was aged probably two and a half by this stage. I just said, 'Where do we head from here?', and he said, 'Look, probably the best you can do at the moment is go home, give him a bit of love and just see if he improves'. We said, 'We understood that you were the paediatrician who could probably send us on to someone else for more specialist needs', and he just said that if we wanted to get a second opinion, go for it — that it was our choice — so I could understand when we left that doctors rooms where Janelle was at the previous fortnight. So we went on to Bendigo and we found a paediatrician down there that helped us down there. He was a lot better. He gave us some avenues to go forward with, and we headed off to Melbourne.

Mrs HOGAN — He referred us to CAMHS to get an assessment, which was a 10-month wait. So, yes, he has got the diagnosis of autism from the paediatrician, but to get any funding or help or assistance we could not do anything else because we needed the writing, I suppose, or for someone to actually do the assessment to say, 'Yes, he is autistic'. So the next 10 months was just us doing stuff with him, because we could not go and see anyone. We could go and see a speech therapist and stuff like that, but because we had no referral to say, 'Yes, he is autistic', we could not do anything with that.

Once he did have his assessment — that all came back 'Yes, he is autistic' — there is this $6000 funding to utilise, but there were no providers in Swan Hill. Everything we had to do, we had to go to Melbourne of course. When you have got three other kids that is pretty tough. We got into the Listen and Learn Centre, which used Tomatis therapy, but they also had OTs, they had speechies, they had psychologists — —

The CHAIR — Where was that?

Mr HOGAN — In Box Hill, on Whitehorse Road

Ms McLEISH — In Melbourne.

The CHAIR — Oh, yes, I know them.

Ms HOGAN — Whitehorse Road it was. We eventually got into that, and it was a two-week stint. So I would go down with Cade for two weeks while Brenten stayed home with the other three kids. Yes, we got funding through that to support that, but it did not include accommodation and it did not include travel. There were so many thousands of dollars that we spent doing that. I would go and do that from Monday to Friday, come home on the weekend and then go back Monday to Friday. We did that on and off for two years, which helped him dramatically. It was really good.

Ms McLEISH — Can I just ask a quick question. So you did a two-week stint how many times in those two years?

Mr HOGAN — We did that five times.

Mrs HOGAN — I think it was probably five per year.

Mr HOGAN — So ten weeks.

The CHAIR — Is that the applied — —

Ms HOGAN — No. We looked into that. That was my next thing. I was actually going to train myself to do that, but I just did not have the time with my family and the kids and everything else, so we looked into maybe doing that in Melbourne because there was somebody in Melbourne who could do that for us. But again it is time, it is commitment, it is money, and we just did not have it. It upends your world. You would do anything for your kids, but at that time it was just too hard.

We did get into Noah's Ark back here, but we got an hour's session a fortnight, so realistically that is nowhere near enough. We needed it every day. The service was great, but we needed it more regularly. So obviously that is why we went to the Listen and Learn Centre, because we could do those two-week stints.

I suppose from there they did assessments again because Cade was then ready for school. You have to go through all the assessments again to see where he is on the spectrum. We decided to put him into Swan Hill Specialist School. He is still there now. It is an absolutely fantastic service.

The CHAIR — So he went through the IQ tests and all of the other application forms that you were required to fill in?

Mrs HOGAN — He did all that again.

Mr HOGAN — Yes.

Mrs HOGAN — Yes, all that. Twice he actually did that. He did that at CAMHS when he first got assessed, and then we did that again when he went to start school.

Mr HOGAN — We did the preschool side of things. It was a bit of a whirlwind at the preschool. We were fortunate enough that at the preschool we went to there was a lady that had a bit of knowledge about dealing with kids with disabilities. Our other children went to a different preschool, but when we got to Cade we had to make a decision to go somewhere else to get that support. They were great.

We were looking, as a family, at going into mainstream, but we also realised when we went and met with the mainstream schools that he was not going to survive socially. He is smart but he just cannot explain how he comes up with the solutions and stuff like that. So we have gone to the specialist school, who have been absolutely fantastic. The support that we have got there has been great. We would like to have more therapies, physios and that. He has not got the straightest walk. His speech has still got to come a long way, but we are getting a lot of great support there with the teachers that we have had there. We have been very lucky there.

Mrs HOGAN — We also went to Mansfield. They run a camp.

The CHAIR — Yes, we have been there.

Mrs HOGAN — It is down at Howqua. That was before he started school, so we as a family went down to that. There was no funding for that, so obviously there is another $5000 or $6000 that you fork out to do that.

The CHAIR — There is a big waiting list too.

Mrs HOGAN — A massive waiting list, yes.

Ms McLEISH — And how did it go?

Mrs HOGAN — Amazing. It was fantastic.

Mr HOGAN — It was also great for the other kids too because they got to meet other kids in the same situation as them.

The CHAIR — So this is the camp?

Mrs HOGAN — Yes, we did the camp.

Mr HOGAN — This is the camp, yes.

The CHAIR — So the six of you went.

Mrs HOGAN — Yes, we did. We went and had a look at the Mansfield school, because that was obviously another option. We could have sent him there for a term, but we just did not go down that road with that. We just did not want to let him go for a term.

Mr HOGAN — We just did not want to split up.

Mrs HOGAN — But the camp was definitely well worth it. It was awesome.

The CHAIR — And is he in grade 6 this year?

Mrs HOGAN — Year 7 now.

The CHAIR — So was he reassessed last year to go across to secondary level?

Mrs HOGAN — Possibly. It is all at the same school, so I suppose it just rolls over.

Mr HOGAN — In the process we have been doing other therapies. We travel to Adelaide every school holidays, or if not, in between for three days. There are different therapies.

Mrs HOGAN — It is an alternate therapy that we are just trying. It seems to be working with him.

The CHAIR — Why Adelaide?

Mrs HOGAN — Because that is where the only lady in Australia who does it is located.

Ms McLEISH — What is that therapy?

Ms HOGAN — It is at the Fravira Clinic. Her name is Elvira. I do not know whether you have heard of it. She does massage therapy. She just warms the blood up and manipulates the bloodstream through his bellybutton. It is just an alternate therapy that we do. Obviously it is not funded, so again that is more expensive.

Ms McLEISH — But then it helps?

Mrs HOGAN — Yes, definitely.

Ms McLEISH — How does it help?

Mrs HOGAN — It just calms him down and just gets the blood flowing through his brain and through his body to different areas.

Mr HOGAN — We have worked out that it probably costs about $12 000 a year to do that, and we understand that it is our choice. But we are seeing a lot of improvement in his demeanour. He is more settled. We can do a lot more things socially now as a family.

Ms McLEISH — It has those benefits.

Mrs HOGAN — Definitely, yes.

Ms COUZENS — Just a quick question: have you got any views on how things can be improved, given your experience from the beginning through to now — —

Mrs HOGAN — If we did not have to have a waiting list — you just lose so much time with waiting lists.

Ms COUZENS — So it is that early intervention side of things that you see as a priority.

Mr HOGAN — Yes.

Mrs HOGAN — Yes, and the earlier you can diagnose it and the earlier you can implement all those things, the outcome is just better.

Ms COUZENS — Are you involved in a support group or anything like that?

Mr HOGAN — No.

Mrs HOGAN — We just do it. We have got our families that are here.

Mr HOGAN — Family and friends have been great.

Mrs HOGAN — We go to football. Our children play football. Cade does not, but he definitely comes to Saturday football with us, and everybody knows him out at the club. He is who he is. They all — —

Ms COUZENS — He does not play because of his behaviours or — —

Mrs HOGAN — He just does not get the concept.

Mr HOGAN — He does not understand it. He likes being around people, but he just does not understand the concept.

Mrs HOGAN — Probably to kick, handball and run and do all that is just — —

Mr HOGAN — That is probably where we need that help at school to get all those. The school is great. We have got a physio that might come twice a week. It is not only Cade, there are a lot of other kids that need the help as well. If they could get something more full time, that would be fantastic. But the biggest concern that we — —

Mrs HOGAN — Our next step now, I suppose, because Cade is turning 13, is what happens to him after school. Where does he go? What happens with work? What other services can he still access here in Swan Hill?

The CHAIR — Will he be eligible under the NDIS?

Ms HOGAN — What is that, sorry?

The CHAIR — The national disability insurance scheme. Will he be eligible for funding under the NDIS?

Mrs HOGAN — I would assume, yes. We get carers support at the minute, but it is $50 a week. It is nothing. It does not even pay to go and see an OT. It is ridiculous.

Mr HOGAN — The biggest decision we have got to make as a family is when he turns 18 and leaves school. Janelle is just going back into the workforce now to become a teacher, so probably I will have to give up my role to assist.

The CHAIR — What do you know about what is available for young people transitioning from the secondary school system into the community and into adult life? Do you know of any support networks or any services in this region that assist with that?

Mrs HOGAN — They have Access employment, which helps with that.

Mr HOGAN — And then they have got a task force up here which employs kids with disabilities. But it is like anything — you can only employ so many.

Mrs HOGAN — By the time Cade leaves school they could be full.

The CHAIR — So there is no social enterprise in Swan Hill?

Mrs HOGAN — Not that I am aware of.

Mr HOGAN — Not that we are aware of, no.

The CHAIR — Does the school run VCAL programs?

Mr HOGAN — Yes, and that is his next step — enrolling into that. It is something that, as I said, we have been mindful of — probably getting ourselves prepared for the next six years to be in that position to help him to go into that role. If it means that we have got to push to help other kids to get into those positions, we will do it.

The CHAIR — Thank you so much.

Mr HOGAN — No worries.

The CHAIR — It is really insightful. You know that you are not alone. It is no consolation, I suppose, but there are so many parents who face that transition into adulthood. It is a very, very difficult we have found as a committee. That transition is very difficult and there are a lot of unknowns about the future.

Mr HOGAN — And that is the thing. We were happy to come along today just so that other families do not have the same experience as us.

The CHAIR — We hope so. Just a last question. Are you okay for your son’s name to be recorded?

Mrs HOGAN — Yes.

Mr HOGAN — Yes, that is fine.

The CHAIR — You are happy with that? Thank you so much.

Mr HOGAN — No worries. Good on you. Thank you.

Witnesses withdrew.