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

Witnesses

Ms Amanda Neil and
Mr Daryl Neil.

The CHAIR — Welcome this morning to Amanda and Daryl Neil. Thank you very much for attending today. All evidence taken at this hearing 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 — you would think I know that off by heart by now but I do not. We have invited you along this morning to make a 15-minute presentation, and as I said to the other families it is up to you whether you speak to us for 15 minutes or if you are happy for us to ask questions. So thank you.

Mr NEIL — We have just got a few notes we will read out. So we would like to thank you for listening to us today. Our family is made up of ourselves and three children. Lachlan is 18 and has an acquired brain injury. Shelby is 15 and Jaxson is eight and has autism, so we experience many challenges on a daily basis. Jaxson was diagnosed with autism in September 2014 at the age of six, which gave us access to the Helping Children with Autism funding of $12 000. The only issue was that we could only use it for 12 months until Jaxson turned seven.

We assessed an OT from Deni and a speechie from Echuca, which was fine for 12 months as Jaxson needed help with motor skills and to develop better speech and social skills. After 12 months we were able to access Medicare to find the services that we were using. My only concern was that it then took us eight months to access an OT through Medicare. This has been very disappointing.

Jaxson also has behavioural issues, for which he is on resveratrol daily. He has sensory processing and auditory processing difficulties, which also affect behaviour and how he deals with the environment around him. We were unable to access a psychologist who deals with autism, as they were either no longer taking new clients or fully booked out.

Jaxson attends Kerang Primary School with around 58 other students. Jaxson looks like any other normal eight-year-old boy. He tries very hard at school to make the right decisions and follow the rules, but as soon as school has finished, more times than not we will see a meltdown. This will consist of screaming, crying and swearing. Jaxson’s schoolwork is failing, and this is showing on reports. He was unsuccessful in getting funding under the PSD. Unfortunately he is with many other children whose IQ is between 70 and 85. The school is unable to provide one-on-one support due to lack of funds. We feel he is falling between the cracks. We are considering keeping him home for the first hour every morning so that Amanda can work with him in the areas needed.

The way we see things are like this: if the rules were changed, we could have used some of the $12 000 to fund support at the school to give him the best chance possible. Just because you turn seven, you are not cured from autism. We as parents were a little lucky that we had some idea of the system from having Lachlan. We knew you had to ask questions to get answers or at least be pointed in the right direction. But in saying that, there is still not enough support when your child is first diagnosed. Parents feel lost and not sure where to get help, and even more so in small country towns. We need more services — for example, OT, speechies, psychologists, more support in schools and, most of all, more funding. Thanks for listening.

The CHAIR — Thank you very much. So does Lachlan live with you?

Mr NEIL — Yes.

The CHAIR — And how do Jaxson and Lachlan get on.

Mr NEIL — Yes — like two grizzly bears with headaches.

The CHAIR — Okay. You do not need to answer that.

Ms McLEISH — So Lachlan had an ABI, did you say?

Ms NEIL — Yes.

Ms McLEISH — How old was he when that happened?

Ms NEIL — He had a stroke in utero.

The CHAIR — So from birth?

Ms NEIL — Yes.

Mr NEIL — I know it is not about Lachlan, but Lachlan attended Swan Hill Specialist School, which was amazing for him. So he finished at the end of last year, and he has started his after school life services now. So he attends Task Force in Kerang two days a week and Murray Human Services — is that what it is called?

Ms NEIL — Yes. Murray Human Services, the Links program and the other is Amaze.

Mr NEIL — Three days a week.

The CHAIR — So what sort of support and advice did you receive after the diagnosis for Jaxson?

Ms NEIL — Not much really. I think it was Aspect or Amaze rang us and said, 'You're entitled to the $12 000; here is a coordinator'. Then basically I just got on the website, scrolled through until I found an OT and a speechie close to Kerang, and Deniliquin and Echuca came up, so we accessed those for 12 months. Like we said, the only concern was as soon as that funding seemed to stop, it took us eight months to access that same OT again. That OT, she was coming once a month, every three to four weeks to see Jaxson.

Ms McLEISH — How far was she coming?

Mr NEIL — Deniliquin, so a bit over an hour.

Ms NEIL — It was like, okay, the money is there; we can access this. But as soon as the Medicare seemed to come into play — was it just a money grab? I do not know . No disrespect to her, because she is an absolutely beautiful person and did an amazing job. But that was just in the back of the mind. Was she just there to grab because that was easy?

Mr NEIL — Easier access.

Ms NEIL — And I know how much was being charged, because we would see that on our invoices.

The CHAIR — So Jaxson was turned down for PSD funding?

Ms NEIL — Yes, just recently.

The CHAIR — And that was because of his IQ alone?

Ms NEIL — No. We seemed to think that it was a language issue. Jaxson's Vineland score was 69. He was actually below the 70, so he met the criteria of autism diagnosis. He met the second criterion. I wish I had brought it now.

Ms McLEISH — Behavioural?

Ms NEIL — Yes, it could have been behavioural. It was to do with the psychology part of things, anyway, but then I think the language brought him down.

The CHAIR — So have you appealed that?

Ms NEIL — No, we have not.

Mr NEIL — We only just spoke about that recently, did we not?

Ms NEIL — Yes, but it all happened right near the end of school, December, and obviously everything shut down and whatnot. I went back through the letter that we got from school, from the education department, and it said you had five days to appeal that decision. Five days is up; it has gone. So unfortunately, with everything else going on — and at that stage too we had a lot of stresses at home, with Lachlan obviously finishing school and going into — —

Mr NEIL — He had anxieties and things like that too.

Ms NEIL — And everything was happening. That was my fault, because I overlooked the letter and did not see that we only had five days.

Ms COUZENS — And support groups, anything like that that you are involved with?

Mr NEIL — No. One pattern from Lachlan that flows on through to Jaxson that we have noticed is — there are lots of main things, but three main things I can think of straightaway are funding, community awareness and having to travel for support. They are three very big things — not enough, lack of community service, especially in small country towns.

Ms COUZENS — We talked earlier about the multidisciplinary teams being based — —

Mr NEIL — Just community awareness on special needs kids, adults, you know. There is not enough.

The CHAIR — How do your boys get on in Swan Hill, out in the community?

Mr NEIL — Sorry, in Kerang. I suppose to paint a picture, everyone knows our boys and they know who they are and what they are, and if they are somewhere they should not be, we get a phone call, which does not happen very often. Probably Lachie manages more easily than what Jaxson does, because Jaxson is not that much of a social child.

Ms McLEISH — How does your middle child go?

Mr NEIL — She struggles, yes, absolutely.

Ms McLEISH — Just because there is always so much going on?

Mr NEIL — Yes.

Ms NEIL — Because she has grown up so quickly, yes. She does not like her brothers. She might.

Mr NEIL — Well, she does, but some days when you see her helping Lachlan, because Lachlan has only got the use of one arm, you think, ‘Are you okay today, Shel?’. They do, but they do not.

Ms McLEISH — And what about at the primary school?

Ms NEIL — They have put in good supports. Like, they are well aware. They have other children in the school with — —

Mr NEIL — Yes, and the new teacher — Jaxson’s teacher this year has been asking a million questions, what he can do and that.

Ms NEIL — They ask lots of questions, ‘What can we do with his anxiety?’. They do, they come and ask us and say, ‘What can we do in this situation? How do we calm him down?’. That has been really good.

Mr NEIL — Triggers and things like that. But funding and specialist support, there is none.

Ms McLEISH — Have any of the teachers at the school gone off and had specialist training?

Ms NEIL — I think some of them have done a few PDs, but it is very hard to get into PDs too. There was one in particular, a Sue Larkey one, which is tomorrow. It would have been great for the school. The school rang up but they were all booked.

Ms McLEISH — Sorry, what one?

Ms NEIL — Sue Larkey. She is an autism guru, and very, very hard to get into. So unfortunately the teachers at the school missed out on that PD tomorrow.

The CHAIR — Thank you so much. I do not have any more questions, but thank you so much coming along, and all the best with your boys.

Ms NEIL — Thank you.

Ms McLEISH — Good luck.

The CHAIR — Are you okay for their names to be published?

Mr NEIL — Yes. No worries. Thank you very much.

Witnesses withdrew.