

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

Witness

Ms Rachel Blandthorn.

The CHAIR — Thank you, Rachel, for coming along this morning. 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. Rachel, we have invited you along for a 15-minute presentation. If you want to just talk to us, that is fine. If you want to present and then we will ask some questions, that is fine too. At the close, can you let us know please if you want your child's name publicly recorded? Over to you, thank you.

Ms BLANDTHORN — I will just give you a brief outline of my own experience in the system. My son had always been difficult to contain. You would turn around for 10 seconds and he would be gone. He was hard to take to basketball games. Each year I would just think to myself, 'Next year it will be a bit easier'. In 2014, when he was four, things were not getting easier; they were escalating. His behaviours, because he could not communicate quickly enough how he was feeling, would come out in his brother being hit, because he is a twin. I had to call the police one day because he took a flyscreen off a window because he wanted to go outside. I think he was about two and a half then. I would turn around and he would be in the pool yard, because he had directed his brother to stand on a chair and pull the latch up while he put a broom in the door. So he has got very good problem-solving skills, which created a lot of life-threatening situations.

When he was four I took him to a paediatrician because I had no clue what I was dealing with. He was a difficult child, but he could talk; he could do everything that his brother was doing. So after a 30-minute appointment I was advised that there was definitely no autism but there could be perhaps a little bit of ADHD, which they would look at later on when he was around five. I just continued on, whatever happened daily we went with. But then I went to a maternal and child health nurse, and she noticed he was having staring episodes. I had not noticed them particularly, but when she pointed it out I did actually notice that he was focusing on things. But she actually thought it was a bit of epilepsy or something like that.

We then went back to the paediatrician, and we got referred for an EEG and things like that, and everything came back fine. In the middle of that, when the paediatrician said there was definitely no autism, he then referred Angus over to the speech pathologist. Now once again with the speech pathologist at the hospital he had like a half-hour appointment, and in my opinion the right questions were not asked about Angus's behaviour, because he went in there and he was just doing what he does — running around, checking everything out, hard to contain and did not talk a great deal. Then they referred us to Noah's Ark.

I went to Noah's Ark, and we were enrolled. Then in the first phone conversation they actually started questioning whether he was actually low IQ, because I did not know you had to be low IQ to be accepted into Noah's Ark. Then we got into an argy-bargy between the hospital and Noah's Ark about who was going to accept him. This was six months after I had taken him to the paediatrician, so I was getting a little bit peeved at that point. I said, 'Well, somebody's taking him'. In the end Noah's Ark accepted him because they had already sent the acceptance letter, even though they questioned low IQ.

We went with Noah's Ark, and that was great. He was probably pretty lucky he got in there, because it was a great service. Then when he started kinder, I had my initial meeting with the kinder and I gave them everything, because you could not contain him. He needed to be in fences and things like that, and if he wanted to do something, he would find a way to do it. They underestimated our conversation and on the first day of kinder he was lost for 10 minutes. He climbed a fence, took a flyscreen off a window and hopped into a tent. I said, 'What happened there?', and they said, 'Oh, he told us he wanted to go inside but we told him it was outside time'. So he just figured out how he was going to get in and, because he knew he was not allowed in there, did not yell out when they were trying to find him.

From day one at kinder they mentioned the possibility of autism. I said, 'No, I've already been to a paediatrician. There's definitely no autism', and then they suggested we get some second opinions. We then went off to Melbourne and I got a second opinion, and just to make sure, the next day I went and got a third opinion. With the first paediatrician we saw in Melbourne, she referred him for speech and psychological assessment and for the multidisciplinary test because she thought he was on the spectrum. And when I went to the next paediatrician the following day at the Children's Hospital, they seemed to think we were on the right

track and we discussed time lines. They said, 'Look, you're best to stay where you are', because we had got in within a month I think to get the further testing done.

That is pretty much where it all started. Thirteen months after my initial appointment and being told there was definitely no autism, we have got autism and we have lost 12 months of therapies. It still is very frustrating that we lost that time, but anyway, things go on. I then searched through the Helping Children with Autism service providers list, which I found was quite a long list on paper but in actual fact those services were not available. There was one speech pathologist in Swan Hill, the OT was through Noah's Ark, which does not deliver the routine OT service, and there was no psychologist. I searched because I wanted him to go to a psychologist for his emotional control and things like that.

The one on the list was in Mildura, which serviced the whole region, and she worked two days a week, so it was impossible to get into her. I was lucky enough that through those phone calls I got hold of another psychologist in Mildura who actually provided services under the mental health services in rural and remote areas program. Angus was eligible for that funding, so we then started going to Mildura fortnightly for appointments, which we still continue to do. The government has since withdrawn that model of funding, and it has now been replaced with psychological therapy services. Now under that funding appointments are limited to 12 sessions a calendar year, so that is effectively half of what Angus had previously been able to access. Now it is the days off work, the days off school, the travel and the cost of the appointment. We are looking at \$800 a day to go to a psychologist appointment. He needs to go, so we continue to do that, and we will figure it out, but that was a big hit when it went from unlimited — you know, what you require — to 12.

The CHAIR — Is that federal funding?

Ms BLANDTHORN — I believe so. He has a psychologist. We had a private speech therapist in Swan Hill, but there was a change of staff, so at that time we actually switched over his speech pathology to the education department. He now sees speech through an education department psychologist at Mildura. I have recently sourced an occupational therapist from Barham. Whenever she comes over, she has other clients over here.

Ms McLEISH — She comes here?

Ms BLANDTHORN — Yes. The last visit we had was a home visit. She has been to his school a couple of times to see him in that environment.

The biggest hurdle we have got, and we are still having, is the funding under the program for students with disabilities. There are seven categories. Angus covers three of them. Two of them he only covers in part. He has the autism, but his speech was too high to get categorised there. He has the behaviours, but he cannot get funded under that, because he has the autism diagnosis. We have got the IQ. He was one point under the cut-off for his IQ test, but they do not believe that score because he did not complete the whole test. Even though he completed enough of the test to get a score, they are not believing that to be reflective of his actual IQ.

This is his application; it is pretty big for a five-year-old. There were countless meetings with countless people. The school put a lot of time into that application, and they were refused the first time and further information was requested. Further information was clarified and they gave him funding, but only short-term funding, so he has only got a year and a half, which is up this May actually, and then he has to go through an IQ test again.

The CHAIR — He will be seven then, yes?

Ms BLANDTHORN — Yes. It is not a big deal, but that first IQ test was absolutely horrendous. He was non-compliant. He did a little bit. It was just horrific. It was horrible to watch. I think he even hit the — —

Ms McLEISH — Did he know what he was doing?

Ms BLANDTHORN — No.

Ms McLEISH — Did he know it was an IQ test?

Ms BLANDTHORN — No. We travelled. We had to travel all the way down to Melbourne. We had to have the speech — —

Ms McLEISH — You had that in Melbourne?

Ms BLANDTHORN — This was all in Melbourne, because there were no services here. I was told at the time that to go through the public system it was going to be a two-year wait. We had already lost 12 months — he was five by this point — and then I was told that, if he is not diagnosed by six, he will not get any funding at all. I think it cost us about \$3000 in total because there were three trips to Melbourne. One was an overnight stay, so we had to have accommodation as well, so it was a really busy time for him. He had the speech test the day before and then went for the psychologist test the next day.

It was a big two days for him, and it did not go well. There is that added stress that, just to satisfy the education department's query, we are going to put that stress on again, even though we cover three categories. And we got the score. We had a score. But anyway!

I then contacted the department of education when that came back, because I was advised that if he received funding under the ID he would be funded until he was six, but then they turned around and they only funded him for a year and a half. It was because there was a lot of discussion about which category we actually apply under, but it was seen that that would be the most successful way to go because, of the other two, autism was just out and the disability one is quite difficult to receive, I believe.

In August I contacted the department of education in Melbourne, the students with disabilities department, where I explained his situation — that he covered multiple areas. I was then advised that external consultants actually make the decisions on the applications. I am finding that they are just professional readers trying to nitpick little bits out of whole applications to work out how they can refuse. I have been told there was one sentence in the psychologist's report that said that he was non-compliant in the IQ test, so that has been used a lot through the reports.

I was actually advised on that day that the government actually currently funded 24 000 students under the program and that was the total amount that they had funding for. I thought that was a surprising comment, because we cannot limit how many children have disabilities just because of a funding number. Then he gave me the contact for the Bendigo office.

I then spoke to the Bendigo office after hearing the story and had the short-term decision reconsidered. It then went back to the external consultants, who unfortunately declined the application again and forwarded an email response to the Bendigo office that was not even factually correct. They said in there he had been given several years funding, and he had only been given a year and a half. It has all been very difficult and frustrating, the whole system.

Then I was on Facebook later last year, after being told the government had no more money to fund children, and I see they have got an Inclusive Schools Fund, which has \$20 million set aside for projects to help make an inclusive school for children with disabilities. I was just dumbfounded, after being told there was no more money, but now we have money for select schools — like, this is not going to help students; it is just the select schools who apply. Imagine how many children we could have helped with \$20 million and if we made the criteria a little bit more inclusive instead of exclusive. The criteria in the funding are brutal. They are designed to limit.

The whole process from diagnosis to therapist is extremely expensive, time consuming and stressful. Then when you get to applying for student with disability funding, the stress just escalates to a whole other level. The criteria are too limiting and rigid, and the transparency of the funding decision and the consistency are questionable. I have heard of children being funded and then kids in the exact same situation not being funded. The education department could not tell me why they refused it. It was all very closed off with the external deciders. It did not seem to flow. There were no reasons behind their decisions.

In that letter back from when they relooked at his application, I was advised that the school has resources to support my son if he is not funded. My question is: how many unfunded students can a school accommodate? These kids have needs and resources that are tight, so how will those needs be met adequately for all the students? It is just similar observations. There are more children at that school that are on the spectrum.

The CHAIR — Which school is your son at?

Ms BLANDTHORN — He is at Woorinen District Primary School. There are six or more in my observations that go to the school, which is quite substantial when it is a small school — we are looking at 90. It has increased from 63 kids last year to 90-something this year, but that is still quite a number, and they are all unfunded. I do not know. I question how many. They cannot refuse children, which you do not want them to do anyway, but they need to be supported so they can help our kids. We have got no other services here. That is where they spend most of their time. That is where they need the help. I think that is about it. It is just such an emotional thing.

The CHAIR — I know. It is very challenging to have to relive some of the experiences, and we have heard some pretty traumatic stories on our journey through this inquiry.

Ms BLANDTHORN — I knew I would get tongue-tied, and I knew I would cry. I did both.

Ms COUZENS — You did well.

The CHAIR — Thank you very much, Rachel. I just wanted to ask a question in relation to the therapies that you have had to — obviously off your own bat — hunt down for Angus. Have any of those been behavioural therapists?

Ms BLANDTHORN — The psychologist deals with his behaviours as well, so not a behavioural therapist as such.

The CHAIR — So if you did have to or did choose to seek out a behavioural therapist, do you know where the nearest one would be?

Ms BLANDTHORN — I would not have a clue, no. I have never come across one.

Ms McLEISH — Can I quickly ask, are they fraternal twins?

Ms BLANDTHORN — Yes.

Ms McLEISH — And your other twin is fine?

Ms BLANDTHORN — Yes.

Ms COUZENS — Obviously you have covered a whole lot of areas in terms of the support you got for your son. Is there anything in particular that you think the committee needs to be aware of or an idea that you have that would improve the process that you have had to go through?

Ms BLANDTHORN — There are so many things, from the beginning of the process, like not being able to access it, having to go to Melbourne three times. A lot of people cannot do that. That was difficult. I obviously had other children I had to leave behind, and off we went. But it was crucial that we went down and got that because there was no option to have it done in Swan Hill. Bendigo had a waiting period, and everywhere else I rang had a long waiting period. If things need to be done, I just like to get them done, so we are likely just to go down to Melbourne.

Ms COUZENS — So is it really more about the beginning of the process that you think needs the major improvement?

Ms BLANDTHORN — I know everything is changing now with the NDIS, and I do not exactly know how that is going to work, but even the list that you got for the HCWA funding was brutal, having to systematically ring and cross off every single person who was not even a provider on that list. I was going through it and thinking, ‘Why are they on here?’. It is not just to make somebody feel good that we have people on a list; they actually need to be service providers. So in the end we could only get one service off that whole list.

Angus’s psychologist is not even on that list. They were actually trying to get on the list, but apparently that process was so time consuming with paperwork that they did not get it done. I actually rang the department of health and said, ‘Why does it take so long to get approved?’, and he was quite cross with me for ringing. He said, ‘Why are you ringing? Why isn’t the service provider ringing?’. I said, ‘Because it’s my son who is missing out on a service’. The service provider is still fully booked.

The CHAIR — Rachel, just one last question in relation to the community that you live in and how you feel Angus is accepted within your community: do you find that he is able to participate in activities, like sport and other recreational activities, or are there barriers to that because of his ASD?

Ms BLANDTHORN — There are definite barriers, but last year he did Auskick out at Woorinen. It is hard for people who do not know. They were very good with him, but it is hard when they do not know how to deal with kids like that. We are not doing football this year, because there are just too many rules. He was quite good with some of them, but some of them he just would not have a bar of. We are going to go and do soccer, which does not have as many rules. But there are no sporting facilities for kids with ASD. There is nobody there to run it.

The CHAIR — Well, there are sporting facilities. I think what you are implying is that there is no-one trained within those — no coaches who are trained.

Ms BLANDTHORN — Yes, they are all just community members who are out there so all the kids can have a kick. They were good with little things, but with the big things they do not have time to constantly tell Angus the rules of every single thing. Like, he did not know he could only tackle the opposition, so of course he was tackling everyone. The other kids would get quite cross with that, so I had to quietly give him the heads-up on that one. But, yes, it is hard because people do not understand autism. They just look at a kid and think, ‘Oh, what a naughty kid. Those parents are such’ — blah, blah, blah. It is not true. And then they have the perception that everyone on the spectrum is the same, which is not true.

I have had a few discussions, but you cannot expect people to be aware — I was not aware until I was put there — so maybe there could be some campaigns or something like that about it, because they are not all the same. They are very different. I look around at his school, and there are totally different aspects of autism with different children.

The CHAIR — Rachel, thank you so much for coming along this morning. We really appreciate it. Just one thing: can you let us know if you want Angus’s name redacted, or are you happy for it to be published?

Ms BLANDTHORN — I am happy for it to be.

The CHAIR — Okay. Thank you very much. We appreciate it.

Witness withdrew.