

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 29 August 2016

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Ms Dianna Lane.

The CHAIR — The committee would like to welcome Ms Dianna Lane. Thank you for coming along to our public hearing 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. Thank you very much for your submission around your 16-year-old daughter with ASD. I now invite you to make a presentation.

Ms LANE — Good afternoon and thank you for the opportunity to speak at this inquiry. My name is Dianna, like you said, and I am a parent of a 17-year-old girl now — she had a birthday in March and I sent the submission in January — Chloe, who has autism and an intellectual disability, ADHD and a sensory processing disorder. I also have two older children aged 24 and 22. I am a primary school teacher and have over 25 years teaching experience. I currently teach today. I am also a member of the Hobsons Bay City Council disability advisory committee as well as a general board member for Interchange Western, which is a disability services provider for the western suburbs.

I nominated for those two positions basically to raise awareness for autism and in the hope that they would be able to offer and provide weekend activities and holiday programs that would be suitable for my daughter to attend. I found that she was able to attend mainstream school holiday programs up until she was 12 years old but after 13 it was pretty much a case of you had to do your own holiday programs and after-school care, and that was a very hard task. There was not anything available, particularly for Chloe who has high anxiety, a sensory processing disorder as well and an intellectual disability. She has extreme behaviour, she is very challenging in that area and she can have meltdowns.

As she has got older the meltdowns have become more pronounced; they are quite violent. For Chloe the activities have to be centre-based because to take her out into the community and into the environment takes a lot. We have to prep her up with a social story, we have got to go and then maybe we will have to leave straightaway. We went to Queensland. We went to the theme parks, we bought the unlimited theme park tickets and we got in there and we had to leave straightaway. It is not uncommon that that happens with us with Chloe. As she has got older we have these major meltdowns with all her mood swings and changes and things like that. She is on medication that is helping to control all of that.

She attends Port Phillip Specialist School and absolutely loves it, because it is a structured environment and she knows the routine. She graduates from that school the year she turns 18, which is our next biggest dilemma because what does she do after that? There is a very limited option of attending a day centre for 18 to 65-year-olds, which is frightening on all levels. Not only that, but they tend to focus more on recreational-type activities and do not provide the much-needed specialist therapy support that they get at the school, such as physio, speech, occupational therapy and psychology. All of that will be ongoing for Chloe; she will need that. These day centres do not provide that.

I have been talking with lots of parents from the school in the same boat as Chloe and we said that there should be another option available to 18 to 25-year-olds, or even 18 to 30-year-olds, to continue in a setting which is based on the specialist school model and that these services are still provided for them because, as we know, children with disabilities do not graduate with the same skill set as their peers so to expect them to transition into adulthood at the same age seems quite unrealistic. That was that point.

This type of 18 to 25 to 30-year-old setting could cater for their specific needs in real-life literacy and numeracy — to still continue what they do at the school — their personal development, computer, industry and work-related areas and have an integrated approach to their development. It would just make more sense — because at 18 they are coping with their puberty and hormones and having these extreme mood swings and things like that — than to throw in a transition where they leave their school that they love at that age. In America they actually stay at their specialist settings until they are all 21. It is the same with England — they are all there until they are 21. Even another three years at the school would be ideal. So that is our next biggest hurdle to face. We found that at 13 there was a really big jump. Services tended to stop for us. Maybe if you were lucky and you had your plan together you could have still accessed some services until they were 15, and now we are finding that as they are reaching adulthood as well.

We know that autism is a complex condition, which is why the programs need to be individualised. We see that some people will go on and earn their PhD, as the lady beforehand was saying, but yet there are others who will need 24/7 care as well. However, I believe we need to use the education system to ensure that the students have the opportunity to be contributing citizens regardless of their disability. They can learn. It is not that they cannot learn; it is just that they are slow at learning. That is what I find with my daughter Chloe and some of the other peers at the school. They follow their own educational and developmental trajectory but they do eventually reach those milestones.

There is the respite for parents. I know you brought that up with one of the other people who spoke. It is really important. For us more so because it tends to be that a lot of these places like Interchange Western want to take them out all the time and for me that spells disaster. We have tried a few places like that and I get the phone call: she is having a meltdown, they cannot control it, it has escalated and we have to bring her home. So we sort of feel like we are prisoners at home a lot because it is hard to take her out. She has very unpredictable behaviour; we do not know what the triggers are for when she has a meltdown. One day it could be fine and the next day it could be — we are hoping it is just an age thing and when all her hormones and everything settle down, so does Chloe. She is on medication to try and help that but sometimes that just does not work as well.

Chloe likes to be in control of the situation, she likes to know what is going on, which is why she is happy in the school system. She knows exactly what is on the next day but she will still go through the schedule the night before and the timetable. She just likes to hear it and go over and over it again. It is very comforting for her to know that.

That is pretty much what I wanted to say. The main important point was the schooling, the post-secondary option, to put that out there as well rather than have her move off into a setting for 18 to 65-year-olds. We have even been looking at her health, too. The same thing will happen there. She leaves the paediatric and moves, which is also very frightening as well for her. It is the safety aspect. If she does have to go to hospital for any reason and she is in there with all adults, it is just mind-boggling. We do have to get a blood test for her and I did ring up Amaze because to even get her into a place to actually get a blood test — we have been waiting two months to try and work her up to it. It is just really difficult. New situations really throw her and us in the family as well.

The CHAIR — Thank you very much, Dianna. I actually liked your submission. I liked your suggestion around support for over 18-year-olds, particularly in relation to the fact that the mental age of many children with ASD is well below their actual age and the time for developmental processes is longer and in some cases end at a certain level. I really like that idea. You mentioned that your daughter was considered too old for the Helping Children with Autism program when she was first diagnosed. I just wonder what other services have been available to her since then.

Ms LANE — Since then? We have used Medicare, the mental health part of that plan. We have accessed that. We did pay privately OTs because Chloe did start off in a mainstream. She did go to the mainstream kindergarten and then she got to year 3 at the school and she was quite a disruption and there were many days I would have to go and pick her up and things like that. So the decision was made to send her to a specialist school where all those services were provided. We did do Uncle Bobs, which was part of the children's hospital, when she was quite young. But I totally agree with the lady beforehand saying that it is quite like a maze out there, and there is no handbook for parents to try to find activities. You might stumble across somebody or talk to somebody and they say, 'Oh, have you tried this?'. I have spent hours too researching the internet for contacts, and reading about all the wonderful things that happen in America for people with autism. In each of their different states they have autism-specific schools, like you were mentioning.

So here in Australia it is quite difficult to find that information and to do the right thing. You do not know if you are. You go along and you think, 'Okay, I need some OT'. So we go along and someone suggests, 'You might need to do the speech therapy'. So okay, we will do the speech therapy. It is a little bit like that. There is a lack of knowledge and awareness out there to tell people where to go.

Now that Amaze has come on board — it used to be called something else previous to that — a lot of people know to ring them up and they are quite proactive in the community in getting it out there that they are around, which is great. I think these days that awareness is developing. More people know somebody that actually does have autism, whereas when we were going through it we felt like we were the only ones on this earth that had a daughter — she was my third, my youngest daughter — with autism.

All our other friends have got children the same age, and then we had this child after a difficult pregnancy. She was diagnosed with global developmental delay until she was seven. The autism diagnosis came in at about five, I think it was, when they said it was that as well. Then we would go along and it would be something else. It was just like, 'She has got the works basically'. But she is verbal, which is probably all that pre-work that we did with her. She is delightful really. We love her to death, but we need a break from her. That is the thing. It becomes quite intense. My husband and I, it is the two of us now. Before she hit puberty, I was able to deal with her on my own or he would be able to take her out, whereas now we both have to go because we just do not know if she is going to have a meltdown. It is like an adult kicking and screaming in the street. That is quite frightening.

The CHAIR — You mentioned, Dianna, what the wait was for you to have your daughter get a blood test, and I have heard through submissions et cetera about the difficulty in accessing medical services for people with ASD. What you think needs to be done to make that better and easier?

Ms LANE — There was a thing on change.org just last week about a hospital. Her child had autism. I think anyone that works with children needs to have some level of education around autism. You know people that do when you actually see them. The Royal Children's Hospital is fantastic. They completely understand what you are going through — we have to access the dental unit there. We can now get her in and sit her in the chair for about 5 minutes before she jumps up and has to run out. But they are wonderful. You know they will have little things to comfort her and calm her down.

So I suppose it is knowing where to go to those places that are autism friendly. Nowadays we actually just ring the home doctor service for somebody to come to the home, whereas when we used to have to take her to the surgery many years ago we would have to sit in the car and then I would run in and say, 'Look, we're just out in the car', because there was no way we could get her into the waiting room. It has made things easier that we actually have the home doctor come, and we can get her to see a paediatrician. It has been the same paediatrician since she was born so she is quite comfortable. She knows she will go up the stairs. She does not sit down in the waiting room because she is quite anxious. We will go in there and then she is out again. It is just new environments and things like that without that social story and going over it and over it and then having the practice and the rehearsal about what is going to happen so there are no great surprises for her. That can help. It is not always the answer, but it can help. It alleviates a little bit of stress on her.

Ms McLEISH — Thank you, Dianna, I just want to touch on the respite angle again. You talked in your submission, and you mentioned earlier, about the community centre where she goes one Saturday a month.

Ms LANE — Yes.

Ms McLEISH — That is great. But if they go out, that is a real disaster. Is that just open for anybody to go to?

Ms LANE — No, they have to have an intellectual disability or autism.

Ms McLEISH — It surprises me then that if they have got autism, they embark on that. Does that happen often?

Ms LANE — That they take them out?

Ms McLEISH — Yes.

Ms LANE — It is interesting. It is a new person that is running it, and I have had many conversations with her, and I have dealt with the person in charge, and they say, 'Well, there are other children that go and they like to go out', which I understand too. They do not want to have it all solely centre based. So I can understand that as well.

Ms McLEISH — They try to mix it up, do they?

Ms LANE — Yes, they try to mix it up and please everyone, I suppose. But when they do take them out — it could be two months before Chloe has had a session — you know, 11 o'clock till 3 o'clock.

Ms McLEISH — The question I want to ask you is about what you said about the United States and the UK about them being older while they are accessing these services. Are they broad programs across the US or state-based? Are they publicly or privately funded? And the same with the UK?

Ms LANE — They are just public. Their public school system goes until they are 21. You know how ours stops at 18.

Ms McLEISH — So their public school system?

Ms LANE — Yes, and even their specialist settings, because over there you are an adult at 21, whereas here we have 18. For us, with people who have an intellectual disability or who attend a special school, it would be great to have them at a centre. I mean it would be ideal if they stayed at their special school until they were 21.

Ms McLEISH — So it is a special school that you are talking about that goes until 21.

Ms LANE — Yes.

Ms McLEISH — And that is just a matter of course across the — —

Ms LANE — Yes. And what they do after that, I am not quite sure.

Ms McLEISH — Have you seen any that you know of that are really good?

Ms LANE — There is one, Monarch, which is an autism-based one. It is called the Monarch school over there in Texas, I think it is. You are familiar with it?

Ms McLEISH — I have heard of it.

Ms LANE — It is wonderful when you look at what they do. I was recently told about a school here in Queensland, but it was more for — —

The CHAIR — In Brisbane?

Ms LANE — I am not sure if it is in Brisbane. I have not actually followed it up, but I did hear that it sounded fantastic as well.

Ms COUZENS — I am not sure how much you know about the NDIS, but do you see that being of benefit to Chloe?

Ms LANE — We are starting to find out about it. They say no-one will be worse off, so that is promising. However, when I talk about the specialist services that Chloe will need probably for life, such as the speech therapist and the physio and the OT, to pay them privately for those sessions the money is not going to go very far. I have heard that for someone with autism their package is probably about \$23 000 a year — something around that figure — and if you think that they need something for five days a week and then you have got to do your private speech and other integrated services, then your money is not going to go very far.

Ms COUZENS — You do not think that it will be more competitive once it starts to roll out?

Ms LANE — That is what everybody tells me.

Ms COUZENS — Yes, I am not saying it will be either. I am just asking you.

Ms LANE — No, I know. I have spoken to people in the department about that. But we need those services. We have not seen them yet. I have done some market research for BUPA, the private health provider. They were more interested when I spoke to them about the nursing home for my dad when we were going around. As we were walking around, they said, ‘These are the temporary rooms for people so that their carers can have a break’. And I thought, ‘Wouldn’t it be great if we could have that for people that have disabilities as well?’. I mean we have cat and dog boarding homes if you go away on a holiday. It is just out of the question for my husband and I to go away on a holiday.

Ms COUZENS — So you have no access to respite at the moment?

Ms LANE — We do actually. We just started with the DHS accommodation place, and Chloe has been twice.

Ms COUZENS — And how has that worked out?

Ms LANE — Well, we have got a few issues, but that is okay. They sort of know how to handle it a little bit.

Ms McLEISH — Is that close to home?

Ms LANE — Sunshine. Yes. It is overnight.

The CHAIR — And that is a disability — —

Ms LANE — Yes. Look, in our life we do not have any spontaneity. Everything is all well planned and regimented. You get to a point in your life when you think, ‘Oh, my goodness’. We sort of tend to live the autistic life as well, having her at home. It is just sort of worrying to think about what is going to happen. Hopefully there will be some great shared accommodation and a carer that can stay there with them.

Mr FINN — Thank you. Now we have today discussed on a couple of occasions the lack of resources in the west of Melbourne, and that has been a particular problem particularly for people like us who live in the west of Melbourne. From your perspective, you are involved in the Hobsons Bay council, what impact is that having on the people that you deal with on a daily or weekly basis?

Ms LANE — I find the council tend to off-load a lot of things. They are the ones that fund partly the South Kingsville community centre and some of the holiday program. Whereas when I first accessed them they used to sort of organise and arrange, and they used to be much better. Whereas they now tend to outsource places to offer these programs and things like that. Look, that is why I did go on the disability advisory committee, because I could see that there was not much happening for me and my child. I mean, we get the 2 hours respite a week from the council and that is so that I can work, and we use it in two 1-hour blocks. And that was one of the first things because they said, ‘Oh no, you need to use it in the 2-hour block’, and I said, ‘But I don’t want that. That’s not helping me’. You know, I am short of this time because Chloe’s special school finishes at this time and I am a bit later.

But, yes, the first thing I did when I joined the committee was to actually tell them about this inquiry, and I rang to see: can local councils put a submission in? So it actually got them thinking. I thought it was a really good thing for them to do, to say, ‘What do we do for people with autism?’. You know, like they say, ‘We do this, this, and we have got this’. It all sounds lovely but I think for somebody that is accessing these services, it is like, ‘Where are they?’. So it was a good starting point.

Mr FINN — Now you have told us today that you have just started some overnight respite.

Ms LANE — Yes.

Mr FINN — How long did it take you to get to that point and how did you go about getting hold of that overnight respite?

Ms LANE — We were on a waitlist for a very long time, and then we actually accessed the Mary MacKillop Family Services too when Chloe was at about 15, 16, and just really uncontrollable. We found her completely challenging in every aspect. So we worked with them and they were able to fast track a little bit of our wait, I suppose, which has been good. But look, she has gone, and we have had two one-night stays, so that is promising. One night and one day, which is lovely.

Mr FINN — But clearly there is a need for much greater respite or much more respite services.

Ms LANE — Yes, and then they said, ‘Look, bring the companion card’, and so now that sort of sets alarm bells for me because I know what Chloe is like. You cannot just take her out, if they are thinking of going to the movies or whatever they are doing. I said, ‘Look, to a park is not so bad, because she feels that she is not so contained’. So I have to always tell them and remind them that, ‘Look, Chloe is coming. It is probably best just to keep her at the house’. There is enough there for them to do at the house.

The CHAIR — Thank you very much, Dianna. We really appreciate your time this afternoon. Good luck with everything and all our best to Chloe.

Witness withdrew.