TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Shepparton — 15 November 2016

Members

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

Staff

Executive officer: Dr Greg Gardiner

Witnesses

Ms De'arne Treacy, and
Ms Trudy Gribben.

The CHAIR — Can I welcome to today's public hearing Ms De'arne Treacy. Thank you very much for attending here 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 for your submission to the inquiry. It is much appreciated. We would like to invite you to make a presentation to the committee.

Ms TREACY — My name is De'arne Treacy. I am the mother of a girl who is now 14 years old. She is on the spectrum. She has been diagnosed with, amongst other things, autism, ADD, a learning disability, and Asperger's more recently, as well as anxiety. She is now attending the Mansfield autism campus at Dookie college. It took us a couple of years to be able to get her a placement there because they only take 14 children, which is the way they like it, and they want it to stay that way because of the ratio of students to teachers. That is at a cost of over $10 000 a year. I also have a partner who is waiting on a heart transplant, so he does not work. He has not worked for two and a half years, so it is quite a financial strain for us to be able to get her to attend that college, but the alternative options are just not even considered because the schools are Notre Dame College and Wanganui, which is zoned, so we may potentially not have gotten in there anyway. They have special needs departments, but the children are still in mainstream, and given her learning disability, obviously that then affects her self-esteem, and then on comes the self-harm talk and those actions. Yes, so it is a challenge.

The CHAIR — Thank you, De'arne, for sharing all of that. When was your daughter diagnosed?

Ms TREACY — It all started when she attended probably child care but mainly prep. She would have been four and a half. I remember going to pick her up from school, and every day the teacher would be like, 'I need to see you, I need to see you'. We started attending different things, like parenting classes, and it eventually got to the point where we were visiting a paediatrician regularly. Then there were OTs and speech therapists — the folder is this thick on the different things that we attended. Eventually diagnosis — probably about five and a half, I think she was. Then of course comes the, 'Let's medicate'. I fought that and fought that until the point you think, 'Well, we've just got to try something', so we tried Ritalin, and I cannot remember the name of the other meds, but they were all pretty much the same sort of thing.

The CHAIR — Was that for behavioural issues?

Ms TREACY — Yes, because one paediatrician was ADHD, and I went, 'Really?', and he went, 'We can probably cross the H out: ADD', and you think, 'Are you just putting it down to get her enough labels so that we can get funding for the school? What is she really?'. It was quite frustrating, and being the first child too, you do not know any different until teachers start telling you.

The CHAIR — Is she an only child now?

Ms TREACY — No, she has got a brother who is 10, and he is fine.

The CHAIR — Was she diagnosed here in Shepparton?

Ms TREACY — We were in Cairns at the time. When we did move back down here five years ago, the referral from the paed up there to Dr Eastaugh down here, even with that referral it took me six months to get in to see him. I came down in the August to look for schools and houses and work, and we moved down at the end of September, so the last term of school, with me thinking early that we will have the funding transferred and she will be right at school — but no, it did not come until the second term of the next year.

The CHAIR — So when she was diagnosed at five and a half did you have access to any early intervention services? Obviously we are talking Northern Territory at this stage?

Ms TREACY — Queensland.

The CHAIR — Queensland, sorry.

Ms TREACY — Yes, north Queensland. Like I said, there were OTs and there were all sorts of different people that we were referred to. I ended up going part time at work so I could accommodate all these extra things, plus being able to pick her up from school was a big thing, because behaviourally she is socially inept. When someone is playing a game and she comes up and says, ‘Can I play chasey with you?’, but they are playing tiggy or something else and they say, ‘No we are playing this’, she does not realise they are not saying, ‘We will not play with you’, they are just saying, ‘This is what we are playing’. Then of course she will have a conniption, and there can be violence and so forth as well because it is once again the self-esteem too; it is back to, ‘Nobody likes me’, but it is not really the case, it just that you do not understand the social skills.

The CHAIR — So how did you find out about the Mansfield autism services?

Ms TREACY — How did we find out? Probably Dr Eastaugh, I think. We were at Kialla Central Primary School, which is a small school at Kialla. There are only about 50 children there, so the principal was quite proactive with finding out different things and including the paediatrician. He used to come to the school. We would have SSG meetings at the school, which we still do now at Dookie. He introduced us to a lot of things that you just do not know are available to you unless you ask the right question. It is like, ‘I did not know that was there’, and if you do not know that you do not know, it is hard to access — —

The CHAIR — And did your daughter do the term at Mansfield or she just went through school here and now she is at Dookie?

Ms TREACY — That is correct. We did not do the Mansfield — —

The CHAIR — We are visiting the Dookie campus this afternoon, so we are — —

Ms TREACY — Yes, Katrine told me that you were heading out there.

The CHAIR — Right, there you go. We will keep an eye out for her. We are very much looking forward to that. Can you tell me what you think is working well for her at that campus?

Ms TREACY — Look, I think the ratio of teachers to students is fantastic, because there are two teachers, or a teacher and an aide in each class of six students — six in each? Yes. Trudy is one of the mums.

Ms GRIBBEN — I have a child out there as well.

Ms TREACY — I asked Trudy to come along as my support today. So the ratio is fantastic. The activities are just amazing. They do yoga and art and swimming in the summer when it is hot enough, and walking every day. They cook — they are very diet conscious. There is a bit of reading and writing in there, believe it or not — they have time for that. But my daughter obviously has a learning disability as well, so she is able to get one-on-one time with her reading and writing and arithmetic — self-esteem comes into play again, so that is really important. Yoga, art, singing — I think one term they might do a bit of dancing?

Ms GRIBBEN — Dancing, yes.

Ms TREACY — So the activities are absolutely amazing. Obviously this is my first year at Mansfield — —

Ms GRIBBEN — I have up to three years.

Ms TREACY — She is more experienced with it all.

Ms GRIBBEN — I am Trudy Gribben. I also have a son at Dookie, and he is 15. His name is Robert.

Ms TREACY — Actually, an interesting story about my daughter and Robert: when she first started, not having the social skill set — —

Ms GRIBBEN — They do not have a lot of filters.

Ms TREACY — No filters, yes. She became very friendly with Robert.

Ms GRIBBEN — And Robert has got very good taste. Usually he can see, ‘She is a nice girl and she is very friendly’, but Robert also does not quite get what is appropriate.

Ms TREACY — As does my daughter.

Ms GRIBBEN — Yes, and Robert, if a girl is being friendly, 'She is my girlfriend'. I say, 'They can just be girls', and it is very hard to have that social understanding of what is appropriate. They became quite friendly.

Ms TREACY — Yes, they did. We discouraged it, as did the teachers.

Ms GRIBBEN — Absolutely, and the teachers had a lot of discussions with them.

Ms TREACY — There are no boyfriends or girlfriends at this school. Then, I do not know, something happened with some action or words or something that was just — —

Ms GRIBBEN — I cannot remember.

Ms TREACY — I do not know what the trigger was.

Ms GRIBBEN — Then they were not talking at all.

Ms TREACY — They just went right off each other.

The CHAIR — Typical teenagers, really.

Ms GRIBBEN — Exactly, and then you go, 'Where are we sitting? Are we sitting here or are we sitting there?', and it is actually quite hard to distinguish for them.

Ms TREACY — It is very difficult, yes, given that there is no escaping when there are only 12 of 14 children, even though they are in separate classes — —

Ms GRIBBEN — But now they are friends.

Ms TREACY — Yes, they are okay — although she told me yesterday that there was something that went down. But she has got the anxiety of her father being in hospital and being not well as well.

Ms GRIBBEN — There is a lot of stuff.

Ms TREACY — There is, there is loads. Everybody has got their things going on, that is what I say to her. You cannot just say, 'Nobody talks to me'. A lot of the children are leaving this year, so they have got the anxiety of what is going to happen next year, 'Where are we going and what are we going to do?'.

The CHAIR — Has she thought about that? Has she thought about what she would like to do?

Ms TREACY — She talks about, 'What job will I get, mum?'. Her very strong talent is drawing, and you will see some of her artwork out there. She has really, really developed that. She has always been a good drawer, but it is just coming out amazingly at the moment. So that is what I am encouraging at the moment and saying, 'Look, if you do some drawing, we'll get a bit of a library, and we can go to the markets and sell those drawings'. I think with these children, the OCD side, their attention to detail is just amazing. When you ask them to tidy a room or something like that, they get down and do it to the nth degree.

The CHAIR — Is there anything in the curriculum out there that you would like to see that is not currently in there?

Ms GRIBBEN — Robert personally needs a lot more confidence in reading and writing and focusing. Robert can go off track so easily. He just cannot or will not do it; he cannot do it. He has a wall up very, very easily. We could go back to lots of stories as well. Robert was actually non-verbal when he was young. We used sign language when he was young, and from 18 months we thought he was just a spoiled boy actually. He had three mothers in the house, because I have got two other girls, so it was always, 'Oh, everyone was making excuses'. You just go, 'I don't think so'. He only had one or two words by the time he was two.

By the time we got to school, I think we had maybe 10, 12 words. and we were using sign language, doing 'normal toilet', whatever. We were at the specialist school; we actually did go to Verney Road early education from age three, because he had to learn to sit, he had to learn to listen and he had to learn to learn, which was great. We were very fortunate to get him there as well, only because I think we jumped on the scenario very quickly. In prep we decided to do four days at Verney Road special school and one day mainstream. Because Robert is incredibly visual — he will pick up signs — and we want him in, as much as we can, mainstream.

He was coping quite well, and he wanted to be social. He did not have the verbal skills to be able to do it, but he wanted to be social. He looked like everybody else. He looks like he fits in, so a lot of the kids did not pick up anything. It was just Robert's funny little way or whatever. Then we decided to actually take him out of Verney Road at the end of prep, because he started spitting and started biting, which largely the other children in Verney Road were doing, because that is a visual of what he could see. We said, 'No, we're stopping those social behaviours'. So we went fully into mainstream.

In grade 1 we had an aide, which was 10 hours a week, which is like okay, and the rest of the time he was either under the table or walking around in circles around the school. But he was there and he was able to participate. He was there, and he was visually able to see what was supposed to be going on in life and what you are meant to do in life: you sit and you stand and you do the correct things. Robert does not like writing, he does not like drawing; he visually cannot get it down onto paper. Computers and games — yes, not a problem. He is very, very quick, gets very obsessed with all of those — incredibly — and gets very grumpy. He is six foot two, so dealing with a 15-year-old who is six foot two is not much fun.

We actually went to Mansfield — we had a travelling teacher — but it took us four years to get a travelling teacher to come to us, and I was on to them from prep, grade 1. It took us four years for one person to come to us one or two days a term from Mansfield. They came into our house, which was great. The first travelling teacher, we did not get along with; I do not think she actually really got Robert or got us. The second one was fantastic. She stayed and she actually put strategies in place. The other one was a lot of talk but not a lot of action. This one was great. We eventually got into Mansfield for one term, and that did change our lives — totally and utterly changed our lives. It totally changed Robert's life. It was the first time he had actually ever been apart from us; he had never been apart from us for a night before then. That was in the first year of official year 7, so he was 13, 14, whatever.

The CHAIR — Yes, they do not start them there until 11 or 12.

Ms GRIBBEN — Yes, that is right. So that was really life changing.

The CHAIR — The focus is on that transition from primary school.

Ms GRIBBEN — Yes, the transition, which is great, because grade 5, grade 6 was absolute hell for us, because it was not as cool to be around Robert. The kids were not so accommodating. The grade 5s, grade 6s, they have got girlfriend-boyfriend stuff going on — like who they like and crushes. He could see it, but he did not understand it, and he wanted to participate but just did not get it. Look, his reading skills have come along — I should not say that. He talks now. He may get his words back to front, he may try to say things. We get what he is saying, but it will be a little bit of a jargon — things thrown in there. He gets the ons and the ofs and the froms all back to front. But Mansfield did change our lives for that one term. As I said, it was the first time he was actually away from us, and I nearly had heart failure. It was like, 'Oh, my God'.

The CHAIR — I am just mindful of time, so I might ask Cindy to ask some questions if that is okay.

Ms McLEISH — I have a number of questions about your daughter. Has she sought out or have you as a family linked her into any programs just for girls with autism?

Ms TREACY — I do not think we have had any information specifically for girls. She has done sand therapy, she has done OT. Through the primary school actually, they organised an OT on a regular basis.

Ms McLEISH — So no out of hours? Because we have heard in different hearings that people have started up almost like a birthday club for girls, where all the girls that did not get invited to parties would ago. Then they would have these things regularly, and they would have different get-togethers where people had organised things. It was probably more city based.

Ms TREACY — I actually do not know many girls. There are only girls out at Dookie that attend, and they are 19, 18. I think one of them is 17.

Ms McLEISH — So within the town you are not even aware of a lot of — —

Ms GRIBBEN — There are a couple in primary I know of, but other than that — —

Ms McLEISH — Another comment I wanted to bring you back to was I think it was the psychiatrist and about 'ADHD or maybe you could drop the 'H'.

Ms TREACY — The paediatrician.

Ms McLEISH — The paediatrician, and you said, 'How do you know what the real diagnosis is?'. Do you feel that sometimes the health professionals are trying to help you by giving you lots of labels so that you can get funding, rather than actually concentrating on what the real issue is?

Ms TREACY — Yes, exactly. Addressing a diagnosis — absolutely. That was a paediatrician in Queensland. I think Dr Eastaugh is much better. Although I do believe the system does make them label more. You know, having one label will not get you funding. An ADD, an ADHD — there is no funding for that one diagnosis.

The CHAIR — So does your daughter get funding?

Ms TREACY — Well, not through the schooling now, no. They used to get funding to get an aide at the primary school, but now we do not get anything.

Ms GRIBBEN — You get about $1000 a year from the government.

Ms TREACY — Do we? Okay, I will have to research that one. That is what I mean: you do not know what you do not know if you do not know what the right questions are to ask either.

Ms McLEISH — I have just got another query. Some people think getting kids with a disability or ASD into mainstream can see them do really well and others have the opposite view. Where you do you sit on this — perhaps what does not work in mainstream?

Ms TREACY — I think socially it just would have been an absolute minefield. I spoke of her anxiety; she is very, very anxious and has very low self-esteem. To be rejected in any form by other students would just crush her, and then of course the self-harm comes into play as well. I think the other social aspects, like we spoke about before between Robert and my daughter — —

Ms GRIBBEN — That would be 10-fold.

Ms TREACY — Yes, and the group of boys who would take advantage of that type of thing in mainstream — —

Ms McLEISH — Is worrying?

Ms TREACY — Is really scary.

Ms GRIBBEN — It is a worry on both sides.

Ms TREACY — Yes, it is. When you are talking 500-plus students, it is just too scary. It is way too scary. Dr Eastaugh agrees with me wholeheartedly. There was no other option.

Ms GRIBBEN — There is just not another option. We were very, very fortunate to get into Dookie.

Ms TREACY — Yes, absolutely.

Ms COUZENS — Thanks for coming along today. We appreciate it. Given that both your children are now teenagers, have you been looking at where to after their secondary education finishes in terms of employment and how that might work for them?

Ms GRIBBEN — It is always on your mind.

Ms TREACY — I have not explored it too much yet because we are just enjoying year 7 knowing that we have a couple of years up our sleeve. But obviously it is on her mind because she talks about it, 'What am I going to do for a job, Mum?'. I think if you can find an employer who is looking for someone, like I said that OCD type of thing where they can get all their ducks in a row, that is going to be ideal — but.

Ms GRIBBEN — It is interesting with these kids. So many of them can do so much.

Ms TREACY — But they are all different.

Ms GRIBBEN — It is their anxiety. Robert has learnt a lot more because his anxiety levels are down, so he actually relaxes so he is able to listen, because it is a small environment in the room. They deal with the scenario because they can see the scenario happening in front of them and so deal with it before it snowballs. I think that is the thing. But as for after school, I am counting three years and I am just horrified. I am really quite frightened.

Ms COUZENS — We heard earlier evidence that having an advocate or a case manager to support people into employment is something that is obviously lacking. Also the future is obviously something that you are considering all the time. Are there any particular areas that you think this inquiry needs to focus on in terms of recommendations — just with your experience and where you see things being important?

Ms TREACY — Dookie is fantastic, but it is only 14 children. There need to be more Dookies. Shepparton is large enough to accommodate at least one I would have thought. Mansfield is tiny. Benalla is — —

Ms GRIBBEN — But there are so many children out there that are really, really struggling at school and they just need a bit more TLC.

Ms COUZENS — But would you expand Dookie or have a whole lot of different little — —

Ms TREACY — The beauty of Dookie is that teacher-student ratio.

Ms GRIBBEN — Dookie has lots of little houses, so you could accommodate the houses because the land is free. It is a big space so they are not feeling crammed in. You have been out there? So it is not feeling crammed, it is not feeling like they are overpowered. They are not feeling like they are overwhelmed in any way or form, other than the flies.

Ms TREACY — But the other thing is they all catch a bus at 8.30 in the morning.

Ms McLEISH — From down town Shep?

Ms TREACY — From Verney Road, just opposite Verney Road, at the shops there.

Ms GRIBBEN — From Verney Road.

Ms TREACY — And they are back here by 3.15. So it is part of their day. That takes an hour out of that, because it is a half-hour trip. It takes an hour off their day, which could be utilised by learning if they were here where they did not have to travel. There are two boys who come all the way from Seymour every day too, so that is an hour's drive to Shepparton and then another half hour there.

Ms GRIBBEN — A lass has been doing it — this is her last year — she has been doing it for six years, twice a day for four years, and it is only in the last years that there is another boy from Seymour now and they are sharing. One is doing the morning, one is doing the afternoon. But every day they travel from Seymour, and she has been doing it for six years.

Ms COUZENS — So that costs $10 000?

Ms TREACY — $12 800 — —

Ms GRIBBEN — The school? $12 500.

Ms TREACY — Is it?

Ms GRIBBEN — Yes, $12 000. It might be because we are a bit older. I do not know.

Ms TREACY — It might be the bus as well. We were $10 800.

Ms GRIBBEN — Yes, it was 10 when we started, so it is 12-something.

Ms TREACY — It includes the bus and everything.

Ms GRIBBEN — Yes, exactly. I would like a little bit more academic out there, because it has been great with Robert learning how to calm and how to deal with the situation. But the academic still needs to be taught and the general knowledge. Some of the kids — one boy could recite Latin to you just about.

The CHAIR — Yes, we have heard about that boy — medieval history and things like that.

Ms GRIBBEN — Yes, history — and do things like that.

Ms TREACY — Yes, they are amazing. They get focused on a certain thing. My daughter will tell you a story about a subject and if you are not au fait with that subject you think, 'Wow, she really knows all about this'. She will study, whether it is from YouTube or whether it is from a movie or whether it is from whatever resource she can find. It is hard to know what is fact and fiction.

Ms GRIBBEN — But the fact that those parents have had to do that from Seymour to here because there was not another option for them is just frightening. Again, they thank their lucky stars that they got in. Your whole life changes, because you cannot go into the work field you have chosen to go into, you have to give up your life to a degree and you cannot go down the path that you had educated yourself to or whatever you had chosen to do because you have to give it up and be there for them.

Ms COUZENS — Yes, and we have heard a lot of that.

Ms GRIBBEN — It just happens 24/7. As I said, one mother has had to do this for six years. But that is what you do for the kids.

The CHAIR — Thank you both very much. De'arne, thank you very much for sharing your story. Clearly it is a difficult situation that you and your husband are facing at the moment and I really appreciate that you have taken the time to come and present to us today. Thank you very much. Good luck to both of you and to your children. I have just one more question. Would you like your daughter's name redacted or are you happy to have it on the public record?

Ms TREACY — I think previously I did say that I was not comfortable with it being there so, yes.

The CHAIR — And Trudy, you mentioned your son's name. Would you like that redacted or are you happy for his name to be on the public record?

Ms TREACY — Trudy probably does not realise that — —

The CHAIR — Everything you have said today is on the public record, including that you have mentioned your son's name.

Ms GRIBBEN — No, I do not mind.

The CHAIR — But you would like your daughter's name redacted?

Ms TREACY — Thanks.

The CHAIR — That is fine. Thank you very much.

Witnesses withdrew.