

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

### **Inquiry into services for people with autism spectrum disorder**

Shepparton — 15 November 2016

#### Members

Ms Maree Edwards — Chair

Ms Cindy McLeish — Deputy Chair

Ms Chris Couzens

Mr Paul Edbrooke

Mr Bernie Finn

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Executive officer: Dr Greg Gardiner

#### Witness

Ms Carole Trotter.

**The CHAIR** — Good morning, Carole. Thank you for coming 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 subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside of 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.

Carole, thank you again for coming along and thank you for your submission to our inquiry. It is much appreciated. You have a son and a granddaughter, is that correct?

**Ms TROTTER** — I do.

**The CHAIR** — We would like to invite you to make a presentation to the committee.

**Ms TROTTER** — Okay. It is with some sadness that I would like to bring the committee up to date with my own autistic son's situation. He lives alone in a department of human services unit and is trying to study IT. He is incapable of handling his finances and has joined a religious sect that accepts his peculiarities. His sister has taken over control of his finances and I top them up on a regular basis. He is depressed and anxious, expressing feelings of failure and inadequacy. He still has emotional and sometimes violent outbursts. He is on an unemployment benefit, still refusing to accept a disability allowance due to his fixed idea of a supposed stigma being attached.

As I talk with other country parents or read of their plight I have become aware of a common theme being expressed. Having an autistic child is a financial and emotional burden. There is usually no respite and no carers to relieve parents of the burden of caring for their child. The family is very often isolated and stressed. The lack of people contact as parents often isolates you to the child's antisocial tendencies, families break up or parents' self-esteem plummets as they become anxious and doubtful of their abilities.

I remember with some gratitude the Mansfield visiting teacher scheme that allowed us some relief but did not prevent the inevitable breakup of the family unit. In many cases there should be an ongoing offer of support for the family unit as well as the child's family respite care. The major benefit of the Mansfield visiting teacher scheme came from having a trained psychologist stay in our family unit offering help or advice as she assessed the overall situation. I thought this was really good because she did not just see the child in an isolated situation; she saw that child on a day-to-day basis.

I can express the relief I experienced on getting a diagnosis in both cases I have been involved with. I still remember the feelings prior to this. I had been isolated from my family and had been advised by my doctor to take Valium. 'That will fix the situation'. When we had a name for the condition we had some idea of what we were dealing with and were able to implement some suitable strategies. I soon became aware that ongoing treatment must be adapted to suit my son's particular needs. My granddaughter was classed as being high functioning and therefore was not eligible for an integration aide in her early years of primary school. The fact that she could talk was marked against her, never mind her extreme high anxiety state, unexplained fears, incontinence — and that was faecal as well as urinary, emotional outbursts, regression and antisocial behaviour. She is now in high school and speaks with despair of her primary years.

We actually looked around Shepparton at all of the different schools and looked for one that may suit her. It resulted in her mother moving from one end of the town to the other so she would be in the zone where she could be accepted by that school. She is still struggling but is very intelligent and is achieving. Often — I suppose it is now continuing — we have private tuition for her because even though she is intelligent she has periods where she just cuts off and does not get the instructions that the teacher has given her. She also says that when in school she cannot ask the teacher for instructions because the boys need to be controlled, so she is missing out.

**Ms McLEISH** — Is that just regular kids just misbehaving a little bit, making a lot of noise?

**Ms TROTTER** — It is regular. In our schools we do have a high percentage of children, they are usually boys, who have social problems and are a problem in the classes. Kathryn just cannot deal with it.

**The CHAIR** — Thank you very much, Carole. Your son was diagnosed 50 years ago.

**Ms TROTTER** — Not quite 50. He would have been diagnosed when he was about six.

**The CHAIR** — And that was back when ASD was referred to as Kanner's syndrome. Is that correct?

**Ms TROTTER** — Kanner's syndrome, yes.

**The CHAIR** — Where did that diagnosis takes place?

**Ms TROTTER** — He was diagnosed by a psychologist, David Cooper, who was here at the time.

**The CHAIR** — In Shepparton?

**Ms TROTTER** — Yes, and he referred us to Mansfield.

**The CHAIR** — Straightaway?

**Ms TROTTER** — Yes.

**The CHAIR** — He was how old?

**Ms TROTTER** — He would have been about seven or eight at that stage.

**The CHAIR** — So you did Mansfield for a term.

**Ms TROTTER** — I finally got people to take notice of him when I sent him to a kindergarten and a kindergarten teacher backed my statement that there was something wrong with this child. Up to then it was just 'Crazy mother'.

**The CHAIR** — We have heard that before from many mothers, who are usually correct in their assessment. Given the lack of support that you probably had over those years for yourself and your son and looking at the time line between when he was diagnosed and now, what do you think would have been the best thing you could have had as a mother, but also for your son, to support you both? Obviously you were very fortunate to have been put in touch with Mansfield, but just more broadly, what do you think has been lacking?

**Ms TROTTER** — I think it would have been ideal if he had had an ongoing one-to-one aide at that time.

**The CHAIR** — So he did not get funding? There was no funding then.

**Ms TROTTER** — No. You had to pay for everything yourself back then. That would have been helpful. I think when I look back that if some of the teachers had been aware — and I think this still happens today; the teachers need to be educated about autism. Until that happens you will have kids in primary school not coping and the teacher is not coping because they do not know how to handle these children. They have got no idea.

**The CHAIR** — We have heard a lot obviously about children with autism. What I would like to hear from you, Carole, is what is the impact of having a child with autism on the family?

**Ms TROTTER** — My family — it ended up breaking us all up. My elder daughter, who is older than Stephen, had a lot of psychiatric problems and ended up suiciding. I think that was a toll on the family unit. My younger daughter also has some symptoms of autism. Very quiet. She just learnt to be quiet because her brother had outbursts all the time. So it affected everybody in the family.

**The CHAIR** — And your granddaughter has recently been diagnosed, or was that a little while ago?

**Ms TROTTER** — My granddaughter was diagnosed when she was about six.

**The CHAIR** — Has she utilised Mansfield autism services?

**Ms TROTTER** — No. I looked at the cost of the school in Dookie and decided it was just too dear, and at that time there was a long waiting list.

**The CHAIR** — Do you know how long that waiting list was?

**Ms TROTTER** — A couple of years.

**The CHAIR** — How long ago was that when you looked into it?

**Ms TROTTER** — I suppose about six or seven years ago. My daughter is a sole parent so she struggles anyway.

**The CHAIR** — So they are on Centrelink benefits?

**Ms TROTTER** — Periodically she does some work. She is now training to be a nurse.

**The CHAIR** — Did your granddaughter receive any support throughout her primary school years? Did she have an aide?

**Ms TROTTER** — No. The school tried to get an aide for her but because she could talk they could not get it.

**The CHAIR** — You mentioned that your son is very into IT.

**Ms TROTTER** — He is into IT. He is trying to pass exams with IT but unfortunately he cannot write.

**The CHAIR** — Have you heard of the organisation Specialisterne?

**Ms TROTTER** — No.

**The CHAIR** — That is an organisation that has just set up in Australia. It helps other organisations employ IT specialists and particularly IT specialists on the autism spectrum.

**Ms TROTTER** — He has got to pass an exam first.

**The CHAIR** — They do not necessarily always have a degree.

**Ms TROTTER** — That is where a big problem is and that has been a problem with him for years. He was very interested in electrical work.

**The CHAIR** — They do not necessarily have to have a qualification.

**Ms TROTTER** — Okay.

**The CHAIR** — But, anyway, we can put you in touch with it.

**Ms TROTTER** — Thank you.

**Ms McLEISH** — Can I just ask first of all, Carole: is your granddaughter your daughter's daughter?

**Ms TROTTER** — Yes.

**Ms McLEISH** — I was just trying to put the relationships into perspective. How do you gauge the emotional health of your son at the moment?

**Ms TROTTER** — The emotional health of my son?

**Ms McLEISH** — Health.

**Ms TROTTER** — None.

**Ms McLEISH** — So is he desperately unhappy?

**Ms TROTTER** — Yes.

**Ms McLEISH** — And does he reach out to you at all?

**Ms TROTTER** — It is very hard to talk with him, for anyone to talk to him, because he has not got good verbalisation skills.

**Ms McLEISH** — What is his living situation?

**Ms TROTTER** — He lives by himself.

**Ms McLEISH** — In the city?

**Ms TROTTER** — Yes. He is actually in Lilydale.

**Ms McLEISH** — Do you visit and see what his premises are like?

**Ms TROTTER** — Yes.

**Ms McLEISH** — Is he meticulous or the opposite?

**Ms TROTTER** — The opposite. My granddaughter says he has got a nerd's property.

**Ms McLEISH** — And diet and things like that, how is that?

**Ms TROTTER** — Not good. He accesses some of the churches for meals. They put on an evening meal. There are about three churches around the area that put on evening meals, and he goes and gets meals from there. If I did not finance him a little bit — not a little bit, a fair bit — he would be out on the street.

**The CHAIR** — Is that a department house that he is in?

**Ms TROTTER** — Yes.

**Ms McLEISH** — Did he have trouble getting that property?

**Ms TROTTER** — Yes. Before that he was with another church group, church organisation, but that church closed up so they had to find other placements for the people in there. So we tried to get the department of human services — finally got it, and he has been in that same place now for about 14 years.

**Ms McLEISH** — How old was he when he shifted from Shepparton?

**Ms TROTTER** — About 18.

**Ms McLEISH** — And how was that move?

**Ms TROTTER** — He went down with his father. His father lived in Lilydale, so he went down there with the hope that he may get some work in a factory. And he did stay at a factory for a long time — for about six years — but he was bullied and finally rang me up and said, 'I can't stay. I'm going home'. Or he just said, 'I signed off. I'm not going back'.

**Ms McLEISH** — But he stayed in Lilydale all of that time?

**Ms TROTTER** — Yes.

**Ms McLEISH** — Okay, so he has essentially just moved from Shepparton to Lilydale?

**Ms TROTTER** — Yes, that is him.

**Ms McLEISH** — You mentioned earlier a 'religious sect'.

**Ms TROTTER** — Yes, yes; the way-out religious sects that do the 'Hallelujah!' and the dancing and all that, speaking in tongues.

**Ms McLEISH** — Do you think he gets any enjoyment out of that?

**Ms TROTTER** — Yes. I cannot understand it really, but he is really obsessed with it. That is how it has become now.

**Ms McLEISH** — Do you think that has calmed him in any way?

**Ms TROTTER** — No, not really.

**Ms McLEISH** — It has become an unhealthy obsession?

**Ms TROTTER** — No, it has been unhealthy, from my angle. Maybe from his angle it has been okay, but from where I sit, no. No, not good, but I cannot stop it. It cannot drop.

**Ms McLEISH** — With your granddaughter, are you fearing because of your son? Do you worry about her?

**Ms TROTTER** — Yes. I think she is going to be a lot better off than what our son is. I just plan on living another 10 years — —

**Ms McLEISH** — I think you probably will. Thank you very much, Carole.

**Ms TROTTER** — Okay.

**Ms COUZENS** — You mentioned your son worked for a long time in a factory.

**Ms TROTTER** — Yes.

**Ms COUZENS** — Was that the first and only job, or has he worked in other areas?

**Ms TROTTER** — He worked a short time in ceramics here in Shepparton, but that closed down. After that he went to Melbourne.

**Ms COUZENS** — Has he worked since he has been in Melbourne?

**Ms TROTTER** — He has done some security work, but it is usually with companies that take advantage of him and give him below-award wages. That could be okay, but Stephen will go to the boss usually and tell them, and he is not very good, as I said, in communication so he does not say it in a very tactful way.

**The CHAIR** — And neither should he if he is being underpaid.

**Ms TROTTER** — It is more than that, actually.

**Ms COUZENS** — But he is currently not working now?

**Ms TROTTER** — Currently, no.

**Ms COUZENS** — Do you think he will get back into the workforce at all?

**Ms TROTTER** — No, I do not think he will ever get into permanent work. If he does get a job, as I said, he usually tells the boss how to run it, and bosses cannot put up with that. As I say, his communication skills are not good so he cannot work things out like you and I could and try and get better deals or get reasonable conditions of pay, or conditions of work for that matter.

**Ms COUZENS** — Do you think his involvement with the religious groups is more about them accepting him? The involvement with the religious groups, do you think that is because he feels more accepted by them?

**Ms TROTTER** — Yes.

**Ms COUZENS** — Do they take advantage of him, do you think?

**Ms TROTTER** — Yes.

**Ms COUZENS** — In what way do you think that happens?

**Ms TROTTER** — He has worked for a long time with them putting up electrical work and sound systems, getting all those going, and he does not get paid for that. He just gets ‘thank you’. That is all part of being part of the group.

**Ms COUZENS** — So it is all voluntary?

**Ms TROTTER** — Yes. At Christmas time he does work at the church first in the morning and then rides — he has got a motorbike — and comes up here for Christmas lunch, late.

**The CHAIR** — So he has a motorbike licence?

**Ms TROTTER** — He does, yes, and he has got a car licence. He has got those, yes.

**Ms COUZENS** — From your experience, and obviously you have got a long history of experience with your son and your granddaughter, what are some of the key messages that you think this committee needs to take back in terms of recommendations?

**Ms TROTTER** — One of the major ones, for children who cannot afford the care, like in the northern autistic school, the Dookie one, is they need to educate teachers how to handle these children — I think that should be enclosed in their curriculum — teach them how to do it so these children are not left out completely.

**Ms COUZENS** — We have started doing that now, thankfully, but we have got a long way to go.

**Ms TROTTER** — The other one I would like to see — I heard you mention about — is advocates trying to get them into work; it is very important. My son has only had contact with employment agencies — they have got no idea.

**Ms COUZENS** — So is he getting Newstart rather than a disability pension? Is that what you were saying before?

**Ms TROTTER** — He is getting a student allowance; he is studying.

**Ms COUZENS** — A student allowance?

**Ms TROTTER** — Yes. He has been getting a student allowance now for a few years.

**Ms COUZENS** — What is he studying?

**Ms TROTTER** — IT — IT and more IT.

**The CHAIR** — At Box Hill TAFE?

**Ms TROTTER** — Yes. He actually went back to school to get his — what do you call it? — matric, and spent the time. They gave him a certificate, which was very good of them I thought — at least it boosted his self-esteem — but he really did not pass.

**Ms COUZENS** — Thank you.

**The CHAIR** — Carole, you mentioned in your submission about pedalling the same treadmill over and over.

**Ms TROTTER** — Yes.

**The CHAIR** — Do you want to perhaps elaborate?

**Ms TROTTER** — That was just a comment about pedalling the same treadmill with a son, daughter and granddaughter.

**The CHAIR** — So your daughter has — —

**Ms TROTTER** — Undiagnosed, yes.

**The CHAIR** — When you talk about the treadmill —

**Ms TROTTER** — That's it.

**The CHAIR** — are you coming across the same issues time and time again — a lack of access to services, a lack of support?

**Ms TROTTER** — Yes.

**The CHAIR** — What about you? Have you reached out for support? Are there any support groups out there that you have tapped into for parents?

**Ms TROTTER** — None. No.

**The CHAIR** — Not even all those years ago. You felt pretty isolated, I imagine?

**Ms TROTTER** — Back then, no. Back then there were only two children here in this area that we knew of. There was Stephen and there was Michael from Mooroopna. They were the only two. So you would not have got any support from anywhere. But these days I think a peer support group would be tremendous, because I know a few children that have got autism who are in the primary care system. If they had a group they could go to, it would help them immensely. I know the RISE Centre does have some, but that is a more general group than just for autistic kids.

**The CHAIR** — And over the years, has your son been involved in any sporting groups? Has he be interested in sport or leisure activities outside of — —

**Ms TROTTER** — Brain-body coordination is not good.

**The CHAIR** — How is his health?

**Ms TROTTER** — Good.

**The CHAIR** — So he is fit and healthy despite the poor diet and lack of exercise?

**Ms TROTTER** — He's okay.

**The CHAIR** — Do you think it would have benefitted him as he was growing up to be involved in sport or other recreational activities where he would have been out socialising more, or would that have just raised his anxiety levels too high?

**Ms TROTTER** — It would have raised his anxiety levels. It would have helped, though. He was a member of a venture club here in Shepparton at one stage. There were two older guys that looked after him. They accepted him for what he was. But any other groups, no.

**The CHAIR** — Do you think that over the years there has been more acceptance of children with ASD or adults with ASD in our community than there used to be?

**Ms TROTTER** — No. I am a member of a U3A group here in Shepparton and there is one guy there who has not been formally diagnosed but I would see he has got autism.

**The CHAIR** — He is on the spectrum.

**Ms TROTTER** — They are fairly intelligent people at that group and they will not accept Neil now. He still goes ahead. He is intelligent; you can pick that up, but he has got these odd characteristics and they do not want to socialise with him. So no, I do not see it being accepted.

**The CHAIR** — That is a generational attitude, but maybe that is changing, though.

**Ms TROTTER** — Maybe. I cannot see it, though.

**The CHAIR** — Thank you very much, Carole. It has been most pleasant to have you present to us today. Good luck with everything. I hope it all works out. Greg will give you the information about the organisation I referred to.

**Ms TROTTER** — Thanks for the opportunity.

**The CHAIR** — Our pleasure. Thank you very much. Carole, you did mention your son's name, which was not mentioned in the submission. Are you okay for his name to be made public?

**Ms TROTTER** — Yes. It has not got his surname, anyway. It was just Stephen.

**The CHAIR** — That is true. That draws to a conclusion today's public hearing. Thank you, Hansard. Thank you everyone. Thank you, secretariat.

**Committee adjourned.**